Prolife Reporter
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PART II

Who will defend MICHAEL?!

A Special U.S. Coalition For Life Report on the National Foundation — March of Dimes

Seven-year old Michael Policastro is the son of Mr. and Mrs. Thomas Policastro of Murrysville, Pennsylvania. Michael was born on February 15, 1969 with Down's Syndrome.

Michael is truly an exceptional child with an exceptional family and an exceptional educational background.

Thomas and Patricia Policastro are officers of the U.S. Coalition for Life and outspoken advocates in the defense of the retarded and handicapped child and his family.

Michael's brother John Philippe and sister Mary Alice are mini-reflections of their parents love and concern for all children — born and unborn — and most especially for little Michael.

Michael received his pre-school education and training from St. Peter's Development Center in Monroeville and is currently enrolled at the Clelian Heights School for Exceptional Children in Greensburg.

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A SUMMARY

AMNIOCENTESIS AND PRENATAL DEFECTS

THE TECHNIQUE

Amniocentesis is the procedure by which the fetal membranes are punctured with a hollow needle and a specimen of the amniotic fluid surrounding the preborn child in the womb is removed. Although the procedure may be carried out transvaginally, the transabdominal route in which the cannula passes through the woman's abdomen and uterine wall, is generally considered to be the preferred method of entry.[1]

The puncture site is determined by previous manual palpation accompanied in many cases by ultrasonography which assists the physician in locating the position of the placenta and the fetus. For diagnostic purposes, amounts of fluid withdrawn range from 5 to 30 or 40 cc., with a 20 cc. maximum during the second trimester.

Care must be taken to avoid puncture of the fetus and the placenta and to minimize the disturbance of the intrauterine environment and avoid placental separation.[2]

As noted earlier in Part I of this report, amniocentesis for purposes of **diagnosis** of prenatal defects is generally performed between the 14th - 16th week of gestation as a "compromise" in order to permit the performance of an abortion of the affected preborn child usually at or prior to the 5th month of pregnancy. On the other hand for truly **therapeutic** uses, that is where the procedure is used to determine fetal maturity or fetal distress or in conjunction with selective dietary therapy or Rh immunization, amniocentesis is generally carried out in the **3rd trimester** of pregnancy.

As a general rule, second trimester amniocentesis for the purpose of diagnosing prenatal defects linked to: sex-linked disease — chromosomal abnormalities — inborn errors of metabolism — should be considered **"nontherapeutic"** since there are relatively few errors where therapy for the affected fetus is available as an alternative to selective abortion.

This conclusion is supported in the section of the **Report of the National Commission on the Protection of Human Subjects of Biomedical and Behavioral Research** prepared by the Research Council of the Battelle-Columbus Laboratory under contract with the National Commission in 1975.

In its lengthy case study on amniocentesis for the diagnosis of fetal abnormalities the Battelle-Columbus staff concluded:

> "Because at this time remedies for a large majority of these abnormalities are not known, most of this research (i.e. amniocentesis) must be classified as **NON-THERAPEUTIC** to the subject fetus."
>
> In an obvious reference to selective abortion however the Battelle-Columbus report notes that "the procedures can be of immediate therapeutic benefit to the pregnant mother."[3]

Detection and Classification of Prenatal Disorders Via Amniocentesis

Today, virtually all **cytogenetic** aberrations, i.e. those disorders related to cell formation, structure, and differentiation, can be detected by amniocentesis and amniotic fluid cell culture and analysis. With the more than 100 currently identifiable metabolic **recessive genetic disorders,** i.e. where the offending gene possesses lesser bio-chemical activity than the dominant, non-affected gene and is therefore more or less completely suppressed in a heterozygous condition, approximately **60** of these can now be detected by amniotic fluid extraction and cell study in vitro. And of the 60 **inborn errors** currently diagnosable by amniocentesis, some **23** have been identified in at-risk pregnancies to date.[4]

It should be understood that amniocentesis **cannot** guarantee an unaffected child since a **single** test is usually administered to women-at-risk for a **specific** disorder. Other disorders may exist therefore which **were not** or **could not** be determined at the time of the amniocentesis procedure.

★Sex-Linked Diseases — Fetal cells obtained by amniocentesis can reveal the sex of the preborn child. This fact is of particular importance if the pregnant patient has a familial history involving a sex-linked genetic disorder such as hemophilia* and the Lesch-Nyhan syndrome.

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*George J. Theobald, Executive Director of the National Hemophilia Foundation, N.Y., issued a statement on the NHF's position on abortion in September, 1972 as follows: "The issue of abortion was raised in 1972 and a poll of National Trustees were taken — an overwhelming majority were "in favor of the right of individuals to abortion as a means of controlling hemophilia." This position however, was never formalized into an NHF policy statement.

Because these are recessive X-linked diseases, they are almost exclusively confined to the **male** population. In a suspected woman carrier of a **male** child, the risk that her baby has the disease is 50%.[5]

Generally, with the sex-linked diseases such as Lesch-Nyhan syndrome, Fabry's disease and Hunter's syndrome where amniocentesis can clearly **identify the affected male child,** only the latter is eliminated via selective abortion.

However, for those sex-linked diseases, not yet identifiable in utero via amniocentesis, **any male child,** affected or not may be aborted merely on sex identification alone.[6]

★Chromosomal Abnormalities — Numerically, the major indication for second trimester amniocentesis and selective abortion is the detection of chromosomal disorders involving either an absence or excess of chromosomal material or a nondisjunction of the gamete. One in every 200 live births indicates a significant chromosomal abnormality involving some 700,000 infants worldwide, and some 20,000 in the U.S. alone annually.[7]

Down's Syndrome (Mongolism) is the most frequently encountered chromosomal disorder. The disorder may be inherited (Translocation D/G) or an accident of cell division (Trisomy 21).

Women in the high risk category for Down's Syndrome include:[8]

1. Women 40 years of age or over
2. Women 35-40 years of age with a previous mongoloid child
3. Mongoloid women

★Inborn Errors of Metabolism — There are currently 40 known metabolic diseases (inborn errors of metabolism) which are diagnosable in utero via amniocentesis and an additional number which may be determined in the very near future.

Metabolic disorders may be diagnosed from amniotic fluid, and cultured and uncultured amniotic fluid cells, assuming that these cells will continue to demonstrate that disorder throughout successive cultures.

"Eventually, in some of the inborn errors of metabolism, therapy for the fetus might be theoretically possible, either directly or via the mother."[9] Two metabolic diseases which are treatable after delivery if detected early are galactosemia and phenylketonuria.

According to Dr. Edwin Seegmiller of the Department of Medicine, University of California, San Diego, La Jolla, California, an institution which has received extensive National Foundation-March of Dimes funding for genetic services and research, the fact that many of these disorders are associated with a neurological disfunction, most of which are not yet treatable, "makes a preventative program through gestational management an especially important mode for control of these diseases."[10]

Tay-Sachs and Hurler's Syndrome are among the better known metabolic disorders which, while relatively rare in the general population, may occur with a high frequency in particular families or among specific ethnic groups. For example, among Ashkenazi Jews, the incidence of Tay-Sachs is one in 30 for the carrier state for this gene, which is ten times the frequency in the general population.[11]

★Sex-Typing — Amniocentesis for the sole purpose of prenatal sex determination and selective abortion apart from considerations of congenital defects, is an area of explosive controversy within the medical profession in general, and geneticists in particular.

In March 1975, the **China Medical Journal** carried a report on the sex prediction program of the Ob & Gyn Department at the Tietung Hospital of Anshan Iron and Steel Company.

Of the 100 pregnant women screened for sex preference, 46 female fetuses were detected — 29 of which were aborted; of the 53 male fetuses, only one was aborted. In one case, fetal gender was not predictable. Accuracy of the testing program reached 93.9% with errors blamed on technical inexperience of researchers rather than the laboratory tests themselves which were carried out via a **first trimester non-evasive sampling of chorionic** villi sloughed into the endocerical canal, rather than second trimester amniocentesis procedures.[12]

Four years before the China experiment in an editorial titled 'Abortion: A Special Demand' in the **Journal of the American Medical Association,** the JAMA editors queried — "Abortion is often called 'therapeutic'. What name should be given to the abortion demanded solely because the sex of the fetus displeases the parents to be?"[13]

More recently the issue of sex-typing via early endometrial aspiration or amniocentesis was raised by Dr. Park S. Gerald of Harvard Medical School at the Bar Harbor Conference on genetic advances sponsored by the NF-MOD in co-operation with Johns Hopkins University of Baltimore. Dr. Gerald noted that this particular demand was created by the public and that elaborate subterfuges were being concocted by couples determined to abort a child of the undesired gender following an amniocentesis procedure carried out for the alleged purpose of determining the existence of a prenatal defect.[14]

The sex-typing-selective abortion controversy has split the pro-abortion geneticists camp down the middle.

Some **National Foundation** geneticists have called the procedure "a 20th Century form of infanticide"[15] and "an inappropriate use of an extremely scarce and expensive technology,"[16] which would strain existing laboratory facilities. Others like M. Neil Macintyre of Case Western Reserve University of Cleveland, a pioneer in the development of techniques to culture amniotic fluid cells for detection of fetal anomalies, have modified their initial public opposition on the basis that the couple has a right to genetic information about themselves and their off-spring and that the geneticist does not have the right to deny them this information on the basis of personal bias. Dr.

Macintyre notes that if the information is routinely denied couples, they will be forced to resort to the falsification of information to obtain the information of the sex of their child. Also that many commercial labs will do the test on amniotic fluid shipped by an obstetrician — with no questions asked.[17]

The NF-MOD position in support of prenatal diagnosis including amniocentesis to all women "at risk of a diagnosable birth defect" **without regard to their attitudes toward abortion,** has already been covered in Part I of the report.

This policy statement has been interpreted by some as a proscription by the National Foundation of amniocentesis for the **sole** purpose of sex-typing.[18] However in light of the National Foundation's insistence that the couple be the **sole** determinant of whether or not to abort the child in the womb — and its toleration of abortion on **male** children in the case of sex-linked diseases where amniocentesis **cannot** as yet identify the **affected** male child and therefore abortion is carried out merely on a 50/50 basis — (the same odds for sex-typing) any anti-abortion **proscription** would appear to be based on shifting sand. As George P. Voss, former Vice President for Public Relations, NF-MOD has argued:

". . . America is composed of a pluralistic society with many different points of view about such things as abortion. Paraphrasing Voltaire, I would defend to the death your right to propagandize against abortion, but I would defend to the death the right of those who propagandize for it. That in a nutshell is what out policy of neutrality is all about. . ."[19]

Clearly, as the Nazi experience has shown, once one is willing to tolerate if not sanction selective killing of an innocent human being (including the selective abortion of a defective child), it would hardly appear reasonable to object to others who wish to carry out a similar program merely because their criteria for selective killing is different from yours.

Amniocentesis — Experimental or Standard Clinical Practice?

*"Amniocentesis performed as recommended by experts in properly equipped and staffed centers produces no greater incidence of fetal or maternal complications than is found in women or fetuses not undergoing the procedure. Tests performed as prescribed give reliable information regarding the specific disorder in question."**

National Foundation-March of Dimes Board of Trustees, May 20, 1976

The safety and accuracy of mid-trimester amniocentesis for prenatal diagnosis; The National Institute of Child Health and Human Development National Registry for Amniocentesis";* **Journal of the American Medical Association, *in press.*

The NHI National Amniocentesis Registry

In October 1975, at the annual meeting of the American Academy of Pediatrics in Washington, D.C., the Department of HEW — National Institute of Child Health and Human Development (NICHD) released its findings of a controlled study showing "conclusively" that amniocentesis in the proper hands is safe for both mother and child.[20]

The NIHCD findings were based on a four-year survey of **1,040 mothers who had had amniocentesis** in the second trimester and their 972 infants, compared with a control group of **992 closely matched mothers** and their 957 offspring.

One third of the amniotic taps were conducted using ultrasound, and one half of the taps were analyzed at the nine centers where amniocentesis took place. The remainder of the tests and culture techniques were conducted at other hospitals or in physician's offices.

Of the 45 women who had undergone amniocentesis and were subsequently diagnosed as carrying an affected child —

— 39 elected to abort

—2 were diagnosed as galactosemic, a metabolic error treatable at birth

—2 cytologic tests of amniotic fluid cells were inconclusive

—of the two children diagnosed for X-linked gene defect one turned out to be normal and the other a victim of hemophilia.

Thirty-six fetal losses sustained by the amniocentesis group were statistically identical with the 32 losses occurring among the 992 controls. No fetal loss was directly related to amniocentesis itself. This appears to be a highly questionable statement in light of the statistics found in the Battelle-Columbus amniocentesis study for the National Commission on the Protection of Human Subjects of Biomedical and Behavioral Research. Pages (15-147) - (15-153) chart transabdominal amniocentesis complications including fetal death for the period beginning 1933-1974, by **year, author, number of patients, taps, percentage of successful taps, indications for amniocentesis** (incl. polyhydramnious, fetal hemolytic disease, genetic defects), **site of puncture, number of complications** and **comments on maternal and fetal complications.**

For example Ryan (1972) lists 6 complications from 291 taps resulting in "Fetal bleeding leading to 3 **intrauterine deaths,** one intrauterine transfusion, and one Caesarian section before fetal bleeding was significant. One questionable amniocentesis in conjunction with premature rupture of membranes." (15-153).

It is unlikely, considering the numbers involved, that the Ryan taps would have remained outside the NICHD period (1971-1975); yet if they were included, the above statement denying **any** fetal deaths due to amniocentesis is obviously untrue.

In subsequent follow-ups and testing at time of delivery and 12 to 14 months later, there appeared to be no difference between the two groups of neonates. Both groups were compared for maternal and fetal complications and the subsequent outcome of their pregnancies.[21]

All nine of the participating obstetrical centers which handled about 50% of **all** second trimester amniocentesis to detect prenatal defects done in the United States during period of the study were recipient of substantial NF-MOD Medical Services and/or Research Grants including:

University of Pennsylvania, Philadelphia
Children's Memorial Hospital, Chicago
Johns Hopkins University, Baltimore
Massachusetts General Hospital, Boston**
University of Michigan, Ann Arbor
Yale University, New Haven
University of California, San Diego
Mt. Sinai Hospital, New York
Harbor General Hospital, Torrance, California

Dr. Duane Alexander, project officer for the National Amniocentesis Registry in releasing the study stated — "Now that amniocentesis has been demonstrated by a thorough going clinical trial to be **safe** as well as **accurate,** it should be recommended for women at risk of having infants with those abnormalities that can be detected by the needle tap."[22]

The Canadian and Swedish Studies

From April 1972 — February 1976, Canada's Medical Research Council conducted a comparable amniocentesis study involving a network of 13 major Canadian medical centers under the chairmanship of Dr. John Hamerton of the University of Manitoba. The findings were announced at the 1976 meeting of the Society for Ob & Gyn of Canada in Toronto.

One thousand, two hundred and twenty amniocentesis taps were done on **990 women** (nearly one fourth required more than one insertion.) The NIH control group was replaced by comparing the results of the study retrospectively with prior vital statistics. The conclusion reached by the Canadian researchers as reported by **Medical World News** was that amniocentesis is "safe, accurate, and reliable" when done at about 16 weeks and "monitored by ultrasound and performed by a trained obstetrician."

There were 33 fetal deaths and 10 neonatal ones among the 1,020 pregnancies, a rate comparable with both the U.S. findings and Canada's known data derived from general fetal and neonatal data.

Of the **62 fetuses** diagnoses as defective via amniocentesis, 51 were aborted, revealing **seven errors of diagnosis** — two involving faulty sex prediction (X-linked conditions) and five due to difficulties with the alpha-feto-protein test used to detect a neural tube defect (NTD). It should be noted that under **ideal** laboratory testing and monitoring conditions, a more than 10% error of diagnosis was discovered by a postmortem study of the aborted babies.

In an earlier and smaller study by Swedish researchers made public in 1973 at the Fourth International Conference on Birth Defects in Vienna sponsored by the NF-MOD, a more cautious position was taken.[23]

The Swedish study conducted over a 3 year period involved 242 amniocentesis taps on **219** women. The procedure was carried out on both high risk and no risk patients between 15-18th week of pregnancy and employed B-scan ultrasonography to locate the placenta. Despite the latter precaution, two women suffered significant transplacental hemorrhaging signaling a possible risk of Rh-immunization.

Of the seven women in the Gothenburg study whose amniotic tap produced brown, discolored amniotic fluid (usually signaling fetal death), one delivered a dead child but **six delivered perfectly healthy babies at full term.**

Three women were diagnosed as carrying a child with a chromosomal defect. Four suffered miscarriages after the amniocentesis and one spontaneously aborted in the 16th week after amniocentesis.

The frequency of spontaneous abortions following amniocentesis, just under 3% for 35 or over group was no higher than in those patients not undergoing prenatal diagnosis.

The Swedish team concluded that amniocentesis is justified for most serious reasons, but **only** under carefully guarded medical conditions and using ultrasonography as an adjunct to the procedure.

Risks and Problems Associated With Prenatal Diagnosis Via Amniocentesis

But is amniocentesis during the second trimester as safe and/or reliable as the NICHD and Canadian and Swedish study would indicate? Should the procedure be classified as a standard diagnostic tool rather than an experimental clinical procedure? What about the psycho-social implications of amniocentesis and selective abortion of suspected defective children, for the mother, for children born subsequently, for the family, and society at large?

A Closer Look

Before addressing ourselves to the issue of maternal and fetal safety and/or reliability of amniocentesis, it may be helpful to highlight some of the observations about the procedure itself —

★ First, amniocentesis is a form of **uterine surgery** which requires an experienced obstetrician and strict aseptic environment.

It is significant to note that when the State of Illinois in late 1974 proceeded to carry out the mandate of Public Act 78-557 by developing a Statewide Prenatal Program for the proper management of high risk pregnancies, one of the obstetrical factors identifiable with an increased incidence of fetal and neonatal morbidity and mortality listed was **uterine surgery**[24] related to previous pregnancies. This risk is obviously compounded where amniocentesis is combined with selective second trimester abortion of the affected child. Little is known about the immediate and long and short term effects of amniocentesis on the preborn child and the mother and on any subsequent children she might bear.

One-third of amniocentesis samples taken in the nationwide trial were analized in the laboratory of pediatrician **Aubrey Milunsky who heads the genetic clinic at Massachusetts General.

This point is driven home by NF-MOD researcher Orlando J. Miller, M.D., in the April, 1971 issue of the **Original Article Series** on 'Intrauterine Diagnosis' (see Part I pg. 18) who suggested that "the current status of knowledge of the biology of amniotic fluid and its contents — including the fetus — is so rudimentary that this fluid must be regarded primarily as an area of research." He also expressed some surprise "by what was *NOT* said during the speakers' consideration of risks associated with prenatal diagnostic studies, i.e., the failure to mention potential long-term risks to children subjected as fetuses to amniocentesis." Further, he admitted "that mental retardation as a result of amniocentesis is a hypothetic danger, but it is not without foundation" since "the removal of the amniotic fluid might reduce the availability of such molecules (i.e., *immunoglobulins*) at a critical period of central nervous system development. (p. 33)

Similar reservations were voiced by Dr. Hymie Gordon of the Mayo Clinic, one of the few nationally recognized prolife geneticists to receive National Foundation funds, in public testimony before the Health and Welfare Subcommittee of the Minnestoa House of Representatives in March, 1971 on the **Genetical Aspects of Abortion.**

He said that during the second trimester of pregnancy when amniocentesis is carried out to determine the absence or presence of a prenatal defect "the little uterus is a rather fragile structure." He wondered out loud how often it might be "torn and irretrievably harmed by the procedure." Noting that at this time "most of the baby consists of brain," he wondered "how often the so called amniotic fluid is in fact the patients' cerebrospinal fluid."

Even with a successful amniotic tap, an accurate diagnosis will depend on the proper utilization (including cultivation and biochemical processing) of amniotic fluid cells and on the proper interpretation of the laboratory results by the geneticist and/or genetic counselor.

★**Maternal Dangers of Amniocentesis** — Among the most frequently reported maternal problems associated with transabdominal amniocentesis are sepsis, hemorrhage resulting from the perforation of the placenta or umbilical cord, isoimmunization in the case of an Rh-negative mother and an Rh-positive fetus, premature labor which may be complicated by infection, and spontaneous abortion. More rare complications include trauma to other abdominal organs including the bowel and the bladder, amniotic fluid embolism as a result of fluid leakage and placenta separation caused by agitation of the intrauterine environment. While a failure to obtain amniotic fluid is not a complication per se, it is a frequent phenomena requiring a repeated tap which obviously increases the possibility of all other risks.[25]

★**Fetal Complications** — The most common fetal complications associated with amniocentesis are injury, hemorrhage associated with puncture, death as a result of amnionitis, errors in diagnostic procedure including failure to identify twinning or multiple fetuses, prematurity resulting from induced labor and death by selective abortion of affected children.

Hemorrhaging may be fatal to an already anemic fetus. Certain adjunct techniques commonly associated with amniocentesis such as amniography (X-radiation, and the use of radio-opaque dye) may induce fetal death. There also remains additional problems with both transcervical amnioscopy and fetoscopy. Ultrasonography appears to present no recognizable dangers to mother and/or child and is commonly used to ascertain gestational age, location of the fetus, location of the placenta and multiple pregnancies.[26]

★**Problems in Amniotic Diagnosis** — An accurate diagnostic test of amniotic fluid can be affected by the cell origin, cell growth in culture and the culture medium.[27]

For example, the possibility of maternal blood admixture may cause an erroneous interpretation of an enzyme analysis, or the amniotic fluid may become contaminated with bacteria.

Cytogenic complications may arise where cells exhibit changes in enzyme activity at different stages of development, or due to the fact that long periods of time may be required to grow sufficient amniotic fluid cells.

According to Dr. Henry Nadler, despite the many factors that might affect the accuracy of prenatal diagnosis, the accuracy of diagnosing a particular genetic defect has been relatively high, i.e., greater than 90%.[28]

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Despite NICHD and National Foundation claims that amniocentesis is a safe and reliable diagnostic tool in skilled hands, it is clear that **even** under strictly controlled laboratory conditions, it is not an *"innocuous"* procedure. There are risks — some known and some not known. As a relatively new medical procedure less than ten years old there is no way of currently assessing the **long term** effects of amniocentesis on the preborn child or the mother.

Further the mass (federally subsidized) promotional campaign currently underway to encourage amniocentesis as a routine procedure for women-at-risk on an outpatient basis will most likely **increase** the number of maternal and fetal complications as well as the number of errors in the diagnosis, cultivation and interpretation of amniotic fluid cells.

The difficulty in achieving a totally aseptic, surgical environment in a general office setting, lack of experience by the attending physician, the lack of ultrasound equipment, and the commercialization of laboratory analysis requiring the transport of specimens through the mail with the likelihood of contamination (and misdiagnosis) are factors almost certain to contribute to a rise in amniocentesis complication and/or diagnostic errors. So is the expected 'overkill' attitude toward amniocentesis by federal health officials.

Government to the Rescue?

Between 1967-1974 approximately 3000 2nd trimester amniocentesis procedures were conducted for the purpose of detecting fetal abnormalities in medical centers across the United States.[29] By 1976, the number has risen sharply to 10,000 annually[30] at an average cost of $150.00 per procedure. [*Ed. Note — amniocentesis is covered by most private and public health insurance programs.*]

Following the publication of the National Institute of Child Health and Human Development results of the **National Amniocentesis Registry study,** Dr. Theodore Cooper, then Assistant Secretary for HEW, announced his support for an expanded national program of amniocentesis. He also voiced his determination to get the Ford administration to support the tax-funding of a network of regional laboratories where amniotic fluid samples could be mailed in for testing, and where personnel could be trained.[31]

According to Cooper, once the laboratories were on a firm footing, they could easily become self-supporting — particularly if government health plans and private health insurers covered the fees. Currently there are only 60 or so laboratories with facilities to carry out amniotic fluid analysis. Even the most experienced of them cannot do more than 200 of these tests a year.[32]

In defending the federal expenditure for the amniocentesis program, Cooper noted that since handicapped children — particularly the mentally retarded — are costly to both the public and their families, tremendous potential savings could be accrued by the selective abortion of defective children especially those with Down's Syndrome (mongolism).[33] However he assured reporters that the poor and welfare recipients would not be coerced into obtaining an abortion against their will should amniocentesis tests detect an affected child in the uterus.

Within two months of the Cooper announcement, the Congress of the United States passed an omnibus health authorization bill providing more than $300 million dollars in FY 1976-78 to fight genetic diseases via research and voluntary testing and counseling programs — including amniocentesis — for couples and women at risk.

Thus the familiar theme song of HEW, repeatedly heard during the Hyde anti-abortion debate, — it's cheaper to abort than support the poor — has already been expanded by HEW health officials to include all defective children in utero for whom no therapy exists or for whom the cost-ratio would be too high to warrant the saving of the affected child's life.

Some observers have suggested that **every** pregnancy should be monitored by amniocentesis to insure that the federally promoted "two-child" ideal required for population stabilization will reflect 'quality' products of conception.

And taking this principle one step further — that all pregnancies be monitored and all defective children compulsorily aborted. Several years ago Ruthe Stein, reporter for the **San Francisco Chronicle,** in an article titled "Genetic Defects — A Furor Over Abortions,"[34] discussed the views of two of the National Foundation-March of Dimes' best known, best funded geneticists — Dr. Charles Epstein of the University of California and Dr. Y. Edward Hsia of Yale, New Haven.

Dr. Epstein takes a **voluntary** approach to the couple's decision whether or not to undergo prenatal diagnosis but a quasi-compulsory stand once they agreed to go through with the amniocentesis. He notes his patients are expected to make an oral commitment to abort a defective child **before** the test is administered.

"Because of the small risk involved, we are not anxious or **willing** to do the procedure if the parents would not terminate the pregnancy," said Dr. Epstein.

Dr. Hsia on the other hand suggests society may want to consider making prenatal diagnosis **mandatory** to determine if the fetus has genetic defects and, if so, make abortion compulsory.

These defects are a tragedy not only for the person and his family, but for society which "may have to shoulder a major share of the medical and social cost of caring for such an individual," Dr. Hsia says.

One of Dr. Hsia's colleagues at Yale, Professor Clement Market in a final exam in Biology of Reproduction (1976) directed his students to write a critical commentary on various population control schemes following a hard-line Malthusian preface including: . . .

- Amniocentesis should be required by law so that any fetus diagnosed as having a serious genetic defect be aborted.
- A world organization or lobby should be established having as its aim the propagation and promulgation of the view that the present Pope's pronouncements and encyclicals on contraception and abortion, and those of similar nature made by any religious ethnic, or racial group, are more dangerous to world peace than the political and economic controversies, national and international, that loom so large in current events.[35]

It is not without irony that in the shift from quantity to quality many of the Ob & Gyn men who have fallen victim to our national birth dearth created by the 20th century version of the Four Horsemen of the Apocalypse — contraception, abortion, sterilization and euthanasia — are being recruited to fill the ranks of medical technicians needed to meet the needs of amniocentesis and selective abortion. Likewise, empty or deserted maternity wards are being converted into genetic laboratories complete with built in disposal service for defective preborn children.

Given the grim track record of the federal government in the promotion and funding of abortion in this counrty and abroad, it requires little imagination to foresee the fetal bloodbath which will follow any federally subsidized prenatal diagnostic program employing amniocentesis and its technical handmaiden, selective abortion.

Which brings us back again to the original question — **Who Will Defend Michael?** and a further exploration of the National Foundation's role in amniocentesis and selective abortion in the form of actual case studies based on NF-MOD policies and programs.

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THE RYAN GRANT

Case Study #1

Induced Abortion As A Cause of Birth Defects

NF-MOD Grant Index **High Risk Pregnancies** April, 1976

Ryan, Kenneth J., M.D.

Boston Hospital For Women,
Boston, Massachusetts $100,000

To begin long-term comparison of about 25,000 pregnancies in women who have and have not previously had induced abortions, and test the theory that prior abortions are associated with subsequent increased risk of miscarriage, prematurity, congenital malformations and various complications of pregnancy which threaten survival of fetus or mother; and that such effects may vary with the method by which prior abortions were induced.

The National Foundation-March of Dimes has steadfastly maintained that **'LEGAL ABORTION LIES OUTSIDE THE PURVIEW OF THE FOUNDATION'** thus justifying its position of "neutrality" in the matter of amniocentesis and **selective** abortion.

The Ryan Grant however, approaches the issue of legalized abortion from a different perspective, i.e. the effects of **elective** abortion (in which 'selective' eugenic termination plays a, **statistically,** minor role) and indicates that at least the perinatal sequela of induced abortion lies within the purview of the Foundation.

Kenneth J. Ryan, M.D. — A Profile

Dr. Kenneth Ryan, who will head the 5-year, one-half million dollar Foundation Study involving 25,000 pregnant women — half of whom had no prior abortion, is a member of the National Foundation's **Basic Research Advisory Committee** which meets annually to evaluate existing and proposed research projects on the causes and prevention of birth defects. He is Chairman of the Department of Obstetrics and Gynecology of Harvard Medical School and Chief of Staff of Boston Hospital for Women, site of the study.

Dr. Ryan is but one of several abortionists known to be serving on the Foundation's research advisory boards.

In 1972, Dr. Ryan, then Professor and Chairman of Obstetrics and Gynecology, University of California School of Medicine, La Jolla, California, was a signatory to an **Association for the Study of Abortion** - statement on abortion which was subsequently published in the **American Journal of Obstetrics and Gynecology** (112, 992-998, 1972).

The statement signed by one hundred professors of obstetrics suggests that "in view of the impending change in abortion practices generated by new state legislation and federal court decisions," it will be expected that doctors perform abortions "simply because the patient asks that it be done."

The statement enunciates the steps necessary for the full nationwide-implementation of abortion-on-command for "predominantly social as well as medical" reasons. Also listed as signatories to the ASA paper were a number of National Foundation grantees and/or scientific advisors including **Dr. Charles E. Flowers, Dr. Norman Kretchmer, Dr. Edward Quilligan, Dr. Morton A. Stenchever, Dr. Donald L. Hutchinson,** and **Dr. Ronald A. Chez.**

As Chairman of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, Dr. Ryan was instrumental in engineering the Commission's approval of live fetal experimentation unrelated to the health or well being of the preborn child who currently enjoys **less** protection than most laboratory animals used by institutions receiving federal monies.

More recently, **Contraception** carried a lengthy article on "Combination Therapy for Midtrimester Abortion: Laminaria and Analogues of Prostaglandins" by **Ryan,** Stubblefield, Naftolin, Lee and Frigoletto. The study carried out at Boston Hospital for Women and the Laboratory of Human Reproduction and Reproductive Biology Harvard School of Medicine involved thirty-four women 13-20 weeks pregnant. Results were compared with a control group of 48 successive cases of patients aborted by a "routine" method, laminaria pretreatment and then intra-amniotic PGF_2 a 40 mg.[36]

Commenting on the results of the study, the authors note that the conventional American method of midtrimester abortion using hypertonic saline, has a maternal mortality rate almost as great as that accompanying delivery at term, and suggest that the laminaria-prostaglandin combination 'therapy' deserves wider clinical application.[37]

One of the 'complications' of the study was the survival of a baby who lived one hour before succumbing in the special care nursery.

The Boston Hospital for Women is one of the few hospitals in the nation where **third** trimester abortions are performed. Fetal remains are regarded as pathological specimens for any abortion under 20 weeks, while a death certificate is necessary for any fetus over 20 weeks gestation if born dead.[38]

In 1974, the institution was the scene of a bitter controversy over screening of the "extra Y" chromosome sometimes referred to as the "criminal" chromosome. The six-year study involving the screening of all baby boys born at Boston Hospital for Women for chromosomal abnormalities, including the extra Y and the subsequent follow-up of 40 of these boys was eventually halted by a citizens group which charged that "extra Y" males would be unfairly stigmatized if their medical records carried such chromosomal information.[39]

Foreign and American Studies on Induced Abortion

There can be no question as to the personal and professional commitment of Dr. Ryan to the furtherance of the abortion cause. Since the selection of an objective researcher is the foundation upon which a valid scientific study must be built, particularly a study involving the explosive public issue of abortion — is not the objectivity of the National Foundation study already jeopardized by the selection of Dr. Ryan as director of the program?

There is perhaps an even more important question which arises from the NF-MOD grant description listed above — which suggests that the researchers will investigate the "theory" that induced abortions may have a deleterious effect on the mother and subsequent pregnancies.

The **fact** of the matter as opposed to the 'theory' is that there already exists an accumulation of scientific-medical literature from a wide variety of sources, both domestic and foreign which links induced abortion, particularly among primigravidae with spontaneous abortion, **prematurity** and congenital malformations in subsequent pregnancies. We highlight below the findings of four important studies and reports on the effects of induced abortion.

THE WYNN REPORT — Some Consequences of Induced Abortion to Children Born Subsequently by Margaret and Arthur Wynn, London, England, 1972. *Copies available from **Marriage and Family Newsletter,** Box 6066, Collegeville, Minnestoa 56321 ($1.25 each).

The Wynn Report lists the following **risks in a subsequent pregnancy** following induced abortion — based on data from England, Wales, Germany, France, Sweden, Hungary, Czechoslovakia, Japan, Switzerland, and Denmark.

*Cervical Incompetence
*Premature Births
*Still-Births
*Placental Damage or Infection
*Sterility
*Prolonged Labor and Complicated Delivery
*Extra-Uterine Pregnancy
*ISO-Immunization
*Infection of Tubes
*Increased Perinatal Morbidity and Childhood Mental-Physical Handicaps.

The following observations are of particular relevance to this report on NF-MOD and selective mid-trimester abortion following amniocentesis:

√ Prematurity resulting from cervical incompetence following induced abortion of first pregnancies is associated with such handicaps as cerebral palsy, epilepsy, mental deficiency, hearing disorders, blindness and autism.

√ The use of selective abortion for the purpose of **preventing** the birth of a genetically defective child, may lead to **increased** perinatal morbidity of children born subsequently.

√ The British Perinatal Mortality Survey of 1963 recommends that women who have had a previous abortion should be regarded as **HIGH RISK** cases in a subsequent pregnancy, and should be "invariably booked for hospital delivery under consultant care."

It is of considerable importance to note that while the National Foundation has consistently underscored the need for intensive care of the high-risk mother and fetus and the dangers of premature — low weight births — nevertheless the Foundation **rejected** and refused to act upon findings of the **Wynn Report** according to author Mary R. Joyce, on the basis that some of the variables were not considered.[40]

THE KOTASEK REPORT — Medical Consequences of Induced Abortion and Its Effects on Subsequent Pregnancy by Alfred Kotasek, M.D., Prague, Czechoslovakia, 1975. [***Copies available from* **The Human Life Review,** *Room 540, 150 E. 35 Street. New York, New York 10016 ($3.00 each).*]

The Kotasek Report is based on the 17-year Czech experience with 2 million legal first trimester abortions and on other foreign sources for mid-trimester induced abortion data, principally the Joint Program for the Study of Abortion (U.S.A.).

First trimester abortion **complications** are divided into four categories:
1) immediate 2) early 3) long-term and 4) latent morbidity becoming apparent during a subsequent pregnancy. These complications are virtually identical to those listed in the Wynn Report.

The author concludes that induced abortions increase subsequent spontaneous abortions, premature births, ectopic pregnancies, ceverical incompetence, sterility and affects the woman's emotional and sexual life.

According to Drs. Thomas W. McDonald and Leonard A. Aaro of the Mayo Clinic the incidence of fetal death during gestation and labor in Czechoslovakia is reported to be twice normal (South. Med. J. 67: 560-66, 1974), and the highest mortality, morbidity and complication rates from induced abortion in the United States will be reported during the next few years.

PSYCHIATRIC SEQUELA TO INDUCED ABORTIONS — According to a special report on induced abortion in the U.S. prepared by Dr. James Ford of *Lynwood*, California, a national medical advisor to the U.S. Coalition for Life in 1975, "the unconsistency, ambiguity, gross bias and methodological inadequacies" of previous abortion studies undermines the validity of current U.S. abortion statistics and data on abortion complications. In terms of solid, objective research findings on the psychiatric complications of induced abortion as opposed to physical complications noted in the Wynn and Kotasek Reports, the dearth of accurate information becomes even more pronounced. Consequently, this editor was especially surprised to discover a recent article in **World Medical News** titled "Amniocentesis and Abortion Woes," which noted the experience of three well-known National Foundation geneticists, **Kurt Hirchhorn, M.D.** of Mt. Sinai School of Medicine; **Dr. Cecil Jacobson,** George Washington University and **Dr. Murray Feingold** of Tufts Medical Center on the psychiatric aftermath of mid-trimester selective abortion following amniocentesis.

According to Dr. Hirchhorn, few of his patients have been happy with their abortions afterwards and many suffered from severe emotional and marital problems. Dr. Jacobson noted that following amniocentesis and selective abortion he obtained best results by guiding subsequent (normal) pregnancies of his patients to term. Dr. Feingold states the necessity of fully informing women of the traumas — both physiological and psychological — associated with mid-trimester saline abortions.

Similar observations have been noted by Cornelia Morrison Friedman, M.D., clinical instructor in psychiatry at Harvard Medical School and consultant at Boston Hospital for Women — the site of the Ryan study. According to Dr. Friedman, post-abortion psychiatric illness may follow where an abortion is carried out for medical indications such as hereditary birth defects. Since such abortions are usually performed in the second trimester of pregnancy, the mother may have more difficulty in denying the humanity of the child she has aborted . . . "Usually . . . the woman has not allowed herself to see the fetus as a baby. Therefore, she does not view the abortion as murder."

However, Dr. Friedman notes that tactful abortion counseling permits a compassionate discussion of the situation with the mother.[41]

It is unclear whether or not the Ryan study will include the psychiatric implications of induced abortion, although such findings would obviously have special significance to the National Foundation amniocentesis program.

THE DIETZ PERINATAL REPORT — In 1975, Helen Dietz, Ph.D., Chairman of the Maternal and Infant Rights Committee of the Family Life League of Illinois issued a statement on a controversial national health delivery scheme designed to establish a multi-million dollar network of perinatal centers throughout the United States for the purpose of identifying expectant 'high-risk' mothers and their offspring. Dr. Dietz' observations and recommendations are important to a fuller understanding of this special report on the NF-MOD and more specifically of the National Foundation's untenable position of 'neutrality' on induced abortion on one hand and its advocacy of a strong national perinatal care program — par excellence — directed at high risk patients, on the other hand.

Addressing herself to the proposed $2.5 million/per six months perinatal center plan, Dr. Dietz states that there are certain ailments that pose a high risk of pregnancy complications such as diabetes and heart disease which are **not preventable** since the present knowledge of the precise genesis of the conditions is incomplete. However there are other conditions which also result in a high risk of pregnancy complications and which **are preventable.** Moreover the latter conditions are much more prevalent than the former among the child-bearing population.

Dr. Dietz points to the absolute necessity of any effectively administered perinatal program to differentiate between non-preventable and preventable causes of high pregnancy risks, and to allocate a substantial portion of the program budget to the latter. Further she suggests that neighborhood clinics and family practice medical centers which serve high risk patients on a day-to-day basis receive the **lion's** share of the allocation rather than intensive care stations at centralized teaching hospitals, on an 80% - 20% basis to correspond to the 20% of 'complicated' pregnancies in the general population.

Citing perinatal statistics in the Austin area of Chicago, which revealed a rise in the death rate among the newborn from 27/1000 in 1970 to 35/1000 in 1974, Dr. Dietz attributed the rise to induced abortion, since the other potential risk factors, principally perinatal malnutrition and a pattern of non-breast feeding had remained stable. She noted that the number of women undergoing abortion has gone up statistically corresponding to the increase in complicated pregnancies in the Austin area. Thus the taxpayer who had been made to pay the cost of elective abortion is now being asked to foot the bill of $2.5 million for a 6 month program to identify high risk mothers whose previous abortions are linked to risk in birth complications in subsequent pregnancies.

RYAN JUSTIFIES GRANT

On December 10, 1976 the **Los Angeles Times** carried an interview by UPI Health Editor Patricia McCormack with Dr. Ryan on the NF-MOD study.

Ryan justified the need for an 'American' study on the effects of induced abortion on subsequent pregnancies dispite numerous foreign studies in this area, on the basis that "no two investigators (foreign) have accounted for all the same factors such as maternal age, state of health, reasons for seeking an abortion, history of childbearing and miscarriage, abortion methods used, and specific abnormalities involved in later problem pregnancies."

Given the current chaotic state of abortion surveillance in the U.S., of course, it is highly unlikely that the Ryan study will be able to draw from data which is error and bias free. And **IF** after five years and five hundred thousand dollars, the Ryan study should conclude that induced abortion has a harmful effect on subsequent pregnancies and can be linked with prematurity and birth defects, will the National Foundation be compelled to mount a public campaign against induced abortion? If so, how could the Foundation maintain a "neutral" stand on induced abortion? OR will the results of the Ryan study merely be used to increase the campaign to develop "safer" methods of pregnancy termination and the need to increase research funding in new methods of **first-trimester prenatal diagnosis** to replace the more dangerous saline and prostaglandin second-trimester abortions?

The High Cost of Silence

In recent years, the National Foundation has given its perinatal research, service and education programs top priority. The criteria for a 'high-risk' patient listed in '76 Facts Booklet include:

1) Pregnant women under 15 and over 40 — non-white and single
2) Poor obstetrical history
3) History of illness such as diabetes
4) Reproductive tract abnormalities
5) Abnormal psychological status
6) Low socio-economic status

There is **no mention** of increased risk to women who have a history of one or more induced abortions despite existing evidence linking the two factors. Neither the Ryan grant nor any other NF service-research grant, is listed under the new format of the widely circulated Facts-1977 brochure.

By the time the Ryan research project is completed — sometime in 1980 — based on the current level of 1,000,000 abortions a year more than 50% of which involve single, **nullipara** women under 21 years of age — we can expect a generation of developmentally handicapped, premature, low weight infants born to hundreds of thousands of high risk mothers who have undergone induced abortion.

Apparently the National Foundation appears to be willing to gamble on an extended period of silence on the hazards of induced elective abortion in order to insure the continued availability of selective abortion necessary for the continuation of second-trimester amniocentesis programs promoted by the Foundation.

Nevertheless we would urge, as the **minimum prerequisite,** that the Foundation support a public education program of **proper informed consent** for women — particularly teenagers — who are contemplating or have undergone one or more induced abortions.

THE FIVE POINTS OF CLASSICAL INFORMED MEDICAL CONSENT

I. Nature of the diagnosis.
II. Nature of the treatment. (including duration)
III. Incidence and nature of risk.
IV. Incidence of effectiveness.
V. Alternative treatments. (including the refraining from any treatment, and including risk and effectiveness)

All patients and health care professionals should be aware that legally speaking no consent to be medically treated can take place unless adequately full disclosure has been made to the patient regarding all five of these points.

Written or oral "consent" without such disclosure is from a legal point of view coercion of the patient.

The health care professional must make a note in his/her records of what disclosure has been made. If risk of death, paralysis, or other danger of serious injury is involved (even though statistically small) the health care professional should obtain the signature of the patient beneath the note documenting that disclosure has taken place.

After disclosure has taken place, the patient may choose to be treated. The patient also has the right to refuse treatment.

Just as the patient may not be coerced into being treated, so also the health care professional may not be coerced into administering treatment which in his/her judgment is non-indicated.

THE RISING TIDE OF EUGENIC ABORTION
A NF-MOD Funded Genetics Conference

Case Study #2

Almost two years after the American Society of Human Genetics Symposium on **Intrauterine Diagnosis and Selective Abortion,** covered in detail in Part I of this report, the National Foundation-March of Dimes financially underwrote and co-sponsored, with the American Genetic Association (AGA) a Symposium on **Advances In Human Genetics And Their Impact on Society** held under the auspices of the American Association for the Advancement of Science (AAAS) in Chicago, Illinois. The proceedings of this important conference were subsequently edited by Daniel Bergsma, M.D. of the National Foundation and published in July 1972 as a **Birth Defects: Original Article Series,** Vol VIII No. 4.

The Mask of 'Moral Neutrality'

As a preface to the symposium proceeding, Drs. Digamber A. Borgaonkar and Saleem Shah, Associate Editors of this NF-MOD monograph note that the explosion of human knowledge in the field of human genetics, raises basic scientific, ethical and social policy issues with profound implications for mankind. And therefore scientific claims of "moral neutrality" must be reexamined in light of these new findings, which may be used for "desirable" and/or "undesirable" purposes — a rather prophetic observation, we believe, in light of the NF's espoused 'neutrality' on selective abortion of defective children.

One is reminded of the truism put forth by Professor Arthur Dyck of Harvard —

"The assumption that the use and application of amniocentesis is a neutral sphere for physicians and society pre-supposes that for physicians and society, abortion is not a moral issue, and that existing or future laws do or will assure that abortions are decided solely by families and physicians. To go that way is not morally neutral, and is not life affirming." "And . . . if both physician and society should be impartial regarding the use of amniocentesis to prevent diseases by eliminating the diseased, what advocate is left for defenseless life?"***

Within the 'pro-life' context of a Constitutional amendment, it should be noted that any Human Life Amendment which would prohibit the destruction of innocent human life via abortion would obviously conflict with the NF-MOD premise that the mother may conspire with a physician, or more aptly a medical technician, to kill the defective child growing in her womb if she so chooses.

The Conference Opens . . .

In his welcoming remarks, **Clair E. Terrill,** Ph.D., President of the American Genetic Association, historically reminisces on the origin of the AGA which began as the American Breeder's Association in 1903. Dr. Terrill points out that the objectives of the AGA are to encourage genetic research and application of genetic principles to plants, animals and **man.** Regarding the latter category, he suggests that since man has to limit his birthrate, it is reasonable that the birth of defective individuals be avoided in a 'voluntary' and 'socially acceptable' way.

The 'way' is explained in greater detail by the next speaker, **Dr. James F. Crow** of the University of Wisconsin, Madison, who highlights the 'enormous' humanitarian gains that can be made by amniocentesis combined with selective abortion in cases of Tay-Sachs disease and Lesch-Nyhan syndrome and similar intrauterine-detectable disorders. While noting that such 'advances' as therapeutic elective abortions may create problems for social or religious orthodoxy, Dr. Crow notes that **"public acceptance of abortion as a means of birth limitation and as a right of the individual pregnant women is now so widespread that a discussion of reservations about therapeutic abortion seems almost anachronistic."**[42]

Conference Papers

Recent Developments in Human Genetics — Their Usefulness and Impact on Society — Digamber S. Borgaonkar, Ph.D.

Dr. Borgaonkar of Johns Hopkins University School of Medicine, reviews the potential conflict between individual and societal genetic choices. The author, a specialist in cytogenetics, makes several remarks on the applicability of avoiding affected children via amniocentesis combined with selective abortion, but also notes that some parents opt in favor of giving birth or choose not to have children at all.

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* Dyck, A.J., "Ethical Issues in Community and Research Medicine" **Linacre Quarterly,** Nov. 1976 pg. 222

**Ibid. p. 221

Commenting on the role of parents as the 'sole authority' over their defective child, Dr. Borgaonkar wonders why there appears to be any problem "when a couple, after obtaining proper advice, choose not to carry on with their unborn child."[43]

On an individual and voluntary level, Dr. Borgaonkar suggests the establishment of public funded-dual purpose genetic centers for genetic counseling and abortion disposal services of defective unborn children. While recognizing that some citizens might equate abortion with "murder" he suggests the effort, at least for the time being, is 'voluntary' and thereby supportable with public monies and facilities. Dr. Borgaonkar concludes his presentation with a review of the potential problems of genetic population studies and screening in the **melieu** of a democratic society.

Practical and Ethical Problems in Human Genetics — Kurt Hirschhorn, M.D.

Dr. Hirschhorn, the well-known National Foundation-March of Dimes researcher from Mt. Sinai School of Medicine, New York, reviews the ethical and social problems posed by new genetic advances from the perspective of —

(1) the individual and family
(2) research scientists and genetic counselors and
(3) the state or governmental representatives.

Defining eugenics as nothing more than 'planned breeding designed to alter the genetic makeup of future generations' the author notes that **positive** eugenics proponent, Herman J. Muller, favored a human genetic study registry and service for planned breeding, while others have favored **negative** eugenics programs which prohibit, voluntarily or by law, reproduction by genetic defectives generally by sterilization.

Another form of **negative** eugenics involves amniocentesis, combined with selective abortion, which Dr. Hirschhorn examines in relation to Tay-Sachs Disease within the Ashkenazic Jewish community.

Dr. Hirschhorn concludes his presentation with a plea for the recognition of the priority of individual rights in any **positive** eugenics program and the application of 'intelligent genetic counseling' in any **negative** eugenics program.

'Our currently changing attitudes about practicing negative eugenics by means of intelligent selection for therapeutic abortion must be encouraged. Basic to this change is a more accurate definition of a living human being . . .'[44]

* * *

AMNIOCENTESIS — LIFE SAVING AND LIFE GIVING?

Professional Responsibility in Prenatal Genetic Evaluation — M. Neil Macintyre, Ph.D.

Of all the presentations made at the symposium, readers will no doubt find Dr. Macintyre's paper on prenatal genetic diagnostic techniques the most illuminating.

After reviewing the potential and short and long term fetal and maternal hazards of intrauterine diagnosis via amniocentesis, and the multi-faceted role of the genetic counselor, Dr. Macintyre of Case Western Reserve University, states his views on abortion.

The author agrees with Dr. Hirschhorn on the need for 'intelligent selection for therapeutic abortion' and supports abortion to prevent the birth of 'a terribly defective child' or 'the emotional and economic destruction of a family unit' but not as a means of population control.

Dr. Macintyre concludes with the following statement: "Incongruous as it may seem to some readers, prenatal genetic evaluation, coupled with therapeutic abortion to eliminate a defective conceptus, is both a life-giving and a life-saving procedure."

The author derives the term "life-giving" from the fact that high risk couples can now try and try again for a normal child, whereas prior to amniocentesis, they might have elected to remain childless, and "life-saving" from the fact that in the past, many high risk couples opt for pregnancy termination on a statistical basis alone, resulting in the abortion of normal children. Therefore, according to Macintyre, "There are, in fact, a number of healthy, desired youngsters living today, whose lives literally have been saved by this type of genetic engineering and I think that's great!"[45]

The twisted logic of Dr. Macintyre, a NF-MOD grantee, is precisely the rationale used by numerous National Foundation spokesmen, more than six years later, and the terms "life-giving" and "life-saving" as applied to combination amniocentesis-selective abortion have become National Foundation passwords, with which the Trojan Horse of eugenic abortion has been made welcome in the enemy's camp.

Recent Developments in Human Genetics and Their Implications for Problems of Social Deviance. Saleem A. Shah, Ph.D.

A lengthy presentation on the nature-nuture controversy and the relevance of genetics to certain mental and behavioral disorders, with specific attention to the xyy chromosomal abnormality, is given by Dr. Shah, Chief, National Institute of Mental Healths, Department of HEW.

Legal and Social Policy Issues Pertaining to Recent Developments in Genetics, Nathan Hershey, L.L.B.

Law Professor Hershey of the Graduate School of Public Health, University of Pittsburgh, reviews the development of law within the perimeters of medical and scientific genetic innovation and "break throughs" including artificial insemination and transplants, and states that traditional religious, moral and ethical considerations create an 'impediment' to dispassionate *discourse* in certain areas of social interaction.

Predicting that anti-abortion efforts are 'doomed to failure' because proponents of liberalization have been able to persuade the public that women have a need to control their own bodies and made the public sensitive to the population explosion issue, Attorney Hershey notes that the early abortifacient IUD has provoked only minor opposition since 'there is no fetus to give the "killing of a human" argument much relevance'.[46]

Hershey attributes early anti-abortion statutes in the United States solely to maternal health considerations by state legislators — an argument lifted out of Roe vs Wade, and later states that while many interest groups oppose abortion for religious or moral reasons, the threats to the woman's health from abortion have been 'virtually eliminated'.

Dr. Crow, whose introductory remarks were highlighted at the beginning of this symposium report, draws the conference to a close with an impassioned prediction that if H. J. Muller could speak to us now, he'd be 'an outspoken advocate of amniocentesis and abortion'. Further he suggests that while at present the right to reproduce at will is regarded as a basic human right he 'cannot see this remaining true much longer' hence the increased significance of birth control including abortion and artifical insemination.

ARE ANTI-LIFE VIEWPOINTS FAVORED BY NF/MOD?

[Editor's note: This original article Series on the AAAS Symposium on Genetic Advances was sent to this editor with a cover letter by Dorothy Davis, Director, Science Information Division, NF-MOD.

According to Ms. Davis, the National Foundation sponsors or participates in a variety of scientific meetings "Where all questions relating to birth defects are freely discussed." "Now and then, in the course of these discussions, individual participants may express personal viewpoints which go beyond the purely scientific in nature and into controversial matters. It should be noted, therefore, that personal viewpoints about such matters will not be censored, but, obviously this does not constitute an endorsement of them by the National Foundation," Ms. Davis concludes.

But if what Ms. Davis states is true, that is "all questions" are "freely" discussed in the realm of birth defects, why hasn't this writer in all the months of research on the Foundation and its publications ever come across a single argument **against** *the selective abortion of defective children and in* **favor** *of the right of defective children to live at a NF-MOD proceeding recorded symposium.*

Why haven't the voices of the small handful of NF-funded pro-life geneticists found a vehicle of public expression at Foundation sponsored conferences on birth defects, if indeed "all" viewpoints are heard? Certainly these basic questions offer food for thought in the continuing debate on NF-MOD policies and programs.]

NF-MOD
LOBBYING ACTIVITIES

"The Whole Truth and Nothing But . . ."

Case Study #3

> "The tax exempt states of the National Foundation is based in part on the requirement that the Foundation shall refrain from lobbying with governmental bodies. Thus, we are **forbidden** in this instance **from attempting to persuade governmental authorities to enact legislation** either anti or pro abortion."
>
> from NF-MOD Policy on Abortion

"Speaking Out on Toxic Chemicals"

In the last session of Congress both the House and Senate passed a Toxic Substances Bill (H.R. 14021 S.776) requiring premarket notification by chemical companies of new industrial and commercial chemicals or chemicals used for a **new** purpose to the Environmental Protection Agency. If after adequate testing, the chemical proved hazardous in terms of cancer induction or produced birth defects, the EPA could regulate or prohibit its manufacture and dissemination entirely.

The House and Senate Conferees passed a compromise bill on Sept. 14, 1976, and the bill went to Ford for his signature.

"The March of Dimes has **urged President Ford** to sign the bill if it reaches his desk."

"Every year billions of pounds of chemicals which are virtually untested and unregulated continue to be produced in industrial processes and used in commercial products," Charles L. Massey, **MOD Executive Vice President, wrote the President** September 28. The bill "would provide a more effective system to safeguard the growing fetus from these external threats produced by man — threats that should not be tolerated," Mr. Massey said.

NF-MOD Maternal/Newborn
Advocate Vol. 3 No. 3 Oct. 1976

"Advocate for Mother and Child"

Improve Administration of Federal Prenatal Programs, Says MOD.

The MOD and the Georgia chapter of the American Academy of Pediatrics (AAP) has **called for the creation of a new comprehensive federal agency** to unify and monitor maternal and child health service . . . The joint proposal has been forwarded to presidential candidates Ford and Carter.

Gabriel Stickle, MOD Vice President for program, said the Federal Government at a minimum should:

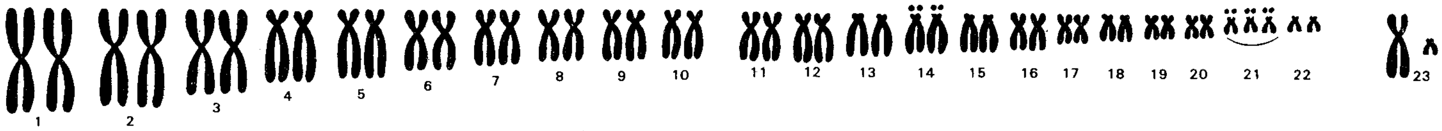
- Expand maternal and infant care (M&IC) projects . . .
- Enlarge recipients of WIC supplemental funding programs . . .
- Enact a national health insurance program . . .

'Legislative Endorsement by NF/MOD'

The statement that the NF-MOD tax statutes prevents the organization from influencing prolife legislation is, in light of the above legislative endorsements (including the controversial national health insurance bill) an obvious falsehood. No tax prohibition exists which would prevent the National Foundation from calling for such a program on Capitol Hill or at the White House.

Life Insurance for the Unborn Child

The greatest threat to the growing fetus today is not chemical pollution but the reality of abortion-on-command which claims a million-plus lives a year. And the best health insurance for the unborn child is a mandatory, from fertilization, National Human Life Amendment.



DOWN'S SYNDROME — Is Abortion The Answer?

Case Study #4

> *"It's easier to get an amniocentesis if there's a history of mongolism . . . in the family. Both families and the society generally would like to cut down on the number of mongoloid individuals — they are a financial and emotional burden on everyone concerned and are pretty useless to themselves as well (a mongoloid child seldom lives to be eight years old).*
>
> *Amniocentesis-derived information that a mongoloid child is in the offing and its subsequent abortion would seem to be both a family and social benefit — and maybe even to the benefit of the prospective child. Only an advocate of "right to life no matter how miserable and unselfconscious" would deny such benefits. But the fact remains that amniocentesis is performed for no other reason than to determine the desirability — individual and/or social — of the child to be born. And there is no serious reason for the test apart from the intent to abort if the results are undesirable . . ."*
>
> *from "Amniocentesis: A Public Moral Question"*
> *an Editorial by Allan R. Brockway*
> **Engage/Social Action * February 1974**
>
> * *A joint publication of the Board of Church and Society of the United Methodist Church — Center for Christian Social Action of the United Church of Christ.*

Causes and Characteristics

Numerically, the major indication for 2nd trimester amniocentesis (in conjunction with *karyotyping*) is the identification of chromosomal *anomalies* — the most common of which is Down's Syndrome or mongolism. Such anomalies reflect either an **absence** or an **excess** of chromosomal material.

In Down's Syndrome, the condition may be brought about by an accident of **cell division.** *(Trisony 21)* or be an **inherited** condition which can be genetically transmitted (Translocation D/G), resulting in the presence of an extra set of 21 chromosome genes.

There is no known 'cure' for Down's Syndrome, therefore, as editor Brockway indicates, the primary reason for doing an amniocentesis on a patient is to detect the Down's Syndrome Child and abort the affected fetus. Worldwide there is little basic research conducted on the disorder — Lejeune of France being one of the few geneticists working in this field. This editor could not find any **major** systematic research program by the National Foundation on Down's Syndrome other than improving amniocentesis and karyotyping, and studies of aging ovaries and chromosomal abnormalities.

Typically, the Down's Syndrome Child, like our coverboy Michael, is characterized by his lovability, his docility and trainability.

Mental IQ's may range from 30-50 and occasionally in the 60-70 range. The degree of severity of mental retardation in such children is dependent on a wide range of factors not the least of which is early identification; supportive educational programs for parents; and continuing developmental-training programs for both non-institutionalized and institutionalized children.

High Risk Mothers

In the category of 'high risk' for bearing a child with Down's Syndrome are

- Women over 40 years of age
- Women who have had a previous mongoloid child
- Mongoloid women
- And women with a family (marital) background of the disorder.

The NF-MOD on Mongolism

Because of its relatively high frequency within the general population as compared to other chromosomal abnormalities, there are numerous references to Down's Syndrome throughout the NF-MOD popular and scientific literature. As noted above, most NF-funded centers for genetic services and research have **regular pre-conceptive screening and counseling centers,** and **amniocentesis-karyotyping services.** The **former** is a valuable service when conducted within a pro-life milieu which gives couples basic knowledge on which to make important decisions related to future child-bearing.* The **latter,** considering the potential danger to mother and/or child, is rarely carried out without abortion as the 'therapy' of choice for affected children.

In the early 1970's, the Department of HEW in co-operation with the National Foundation funded an educational project carried out by David W. Smith, M.D. and Ann Asper Wilson of the Dysmorphology Unit, Department of Pediatrics, University of Washington Medical School, Seattle, Washington. The end product was one of the best comprehensive guides on the causes, characteristics and acceptance of the Down's Syndrome Child for parents, physicians and other persons concerned with the education and care of these special children, titled **The Child with Down's Syndrome (Mongolism).**[47] In addition to its easy readability and updated research, the book features the exquisite photographs by David Gluck of Alison, a 14 month old child with Down's Syndrome.

In scanning the book it appears unconceivable that it should contain even the slightest suggestion that children such as Alison should have **never** been born at all. Yet Chapter I contains two specific references to amniocentesis and selective abortion of mongoloid children. We quote —

> "... amniocentesis, usually cannot be done before the thirteenth or fourteenth week of pregnancy. Chromosomal studies on the cultured cells, if successful, will usually yield a result within two or three weeks. The parents can then decide whether they wish the pregnancy to be terminated or not. This procedure is currently being performed in some of the larger medical centers . . ."
>
> "Ideally, it would be worthwhile to perform amniocentesis and chromosome studies in all pregnancies and thereby prevent the birth of babies with Down's Syndrome or other chromosomal abnormalities, which occur in one in 200 babies born . . ." (p. 19)
>
> In summary ". . . For those parents who have a relatively high recurrence risk for Down's Syndrome, future pregnancies can be monitored by chromosome studies on fetal amniotic cells, with early termination of the pregnancy when the fetus is destined to have Down's Syndrome." (p. 20)

The blunt and warped position which upholds the killing of a defective person as a form of 'therapy' for distressed parents or a money-conscious society has been publicly echoed by numerous NF-MOD spokesmen and researchers.

> "... On the whole I am heartened. I am reminded of a young woman who had three mongoloid sisters. When this young woman got married, she was naturally frightened about having a child. Even so, she became pregnant and had amniocentesis which identified the fetus as unmistakably a mongoloid. Following abortion, she had two normal children. In a case like that, this awesome technique for invading the world of the unborn more than justifies itself. So does the young couples courage in trying again — successfully."
>
> Interview with Dr. Virginia Apgar**
> Vice President, march of Dimes
> **Family Weekly**[48]

One of the best funded NF-MOD Geneticists, Dr. Charles Epstein of the University of California (see Part I pages 5, 7) has stated "Amniocentesis has the potential of preventing large numbers of mongoloid children . . . for me, it is justified to terminate a mongoloid pregnancy."[49]

In August, 1974, the National Institute of Child Health & Human Development (NICHD) of HEW announced the beginning of a national public education program designed to reduce the incidence of mongolism by about 30%. An NICHD spokesman in Los Angeles noted the program would be directed at women in the child-bearing age, especially women over 35 years of age. NF-MOD Researcher, Dr. Michael Kaback of UCLA (Harbor General Hospital) was interviewed at length on mongolism and amniocentesis in the **Los Angeles Times.**[50]

According to Dr. Kaback, a high percentage of spontaneous miscarriages involve abnormal chromosome makeup, including children affected with Down's Syndrome therefore "families electing abortion are not that different from nature."

"The purpose of the education campaign," he added "is not to tell people what to do — but make them aware of the alternatives."

The only "alternative" however to the **birth** of a mongoloid child which Dr. Kaback mentions is the killing of the child in the womb via abortion. He defends amniocentesis combined with selective abortion against 'right-to-life' critics by noting that normal children are permitted to live.

Human Life — The Cost Benefit Ratio

The economic implications of letting Down's Syndrome children live rather than aborting them has not escaped HEW-NICHD bureaucrats. Two influential HEW officials — Dr. Theodore Cooper and Dr. Duane Alexander — have noted the 10-fold savings to the State from a national program of amniocentesis and selective abortion designed to stamp out mongolism and snuff out mongoloid children.[51]

The cost-benefit ratio of birth over abortion for mongoloid children has become a topic of increasing interest among a wide range of academic-education-scientific-political personalities.

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* For a comprehensive discussion of genetic screening programs see **Genetic Screening: Programs, Principles and Research,** Barton Childs et al., National Academy of Sciences, Washington, D.C., 1975.

**The late Dr. Virginia Apgar was the creator of the famous Apgar Score for *Newborns.*

Amitai Etzioni, author of **Genetic Fix,** has estimated that between 1970-1980, 57,348 - 82,680 mongoloid children born in the United States and that tax-funded institutionalized care for such children runs about $1.7 billion annually.[52] In the same article he calls for a national eugenics policy and an expanded federal program of amniocentesis-selective abortion but cautions against compulsory abortion merely to save funds and/or medical resources. The latter proposal, Etzioni suggests, no one in "his right mind" would support.

Geneticist J. Edwin Seegmiller of the University of California, LaJolla, San Diego puts the annual price tag for the tax-supported **maintenance** program of mongoloid children at $1.5 billion.[53]

One of the most comprehensive studies chromosomal abnormalities from a cost-benefit perspective is presented with chilling efficiency by A. Milunsky in **"The Prenatal Diagnosis of Hereditary Disorders",**[54] and reproduced in the Appendix of the **Research on the Fetus** Report of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research — 1976-(p. 15-163).

According to Milunsky's calculations, "the birth of 7,667 chromosomally defective offspring in one year could ultimately cost society in excess of 2 billion dollars — about thirty-two times the cost of prevention through prenatal diagnosis and therapeutic abortion . . . in twenty years of present costs (which of course will not apply) the cost will have grown to about 40 billion dollars . . ."

The figure 7,667 represents the number of seriously defective offspring born each year to 400,000 mothers over 35 years of age in the United States. The cost of providing amniocentesis and prenatal genetic studies on a routine basis for these 400,000 women is approximately $60 million to which must be added the cost of a second trimester abortion ($400 for saline — $800 for hysterotomy) for the estimated 7,667 women carrying a defective child for a total of **$63.4 million.**

On the other hand, life-time care of the 7,667 defective children was estimated to be approximately **$2.3 billion.**

ENGLAND'S DOWN'S SYNDROME PROGRAM

— Payment for a Scruple —

The use of amniocentesis combined with the selective abortion of affected children was recently offered as a "solution" to reducing the number of live-born mongoloid children in England and Wales by 14 percent.

According to David Owen, Minister of State for Health, "A specific program for the prevention of handicapped (children) should be on the agenda for action by every area health authority."

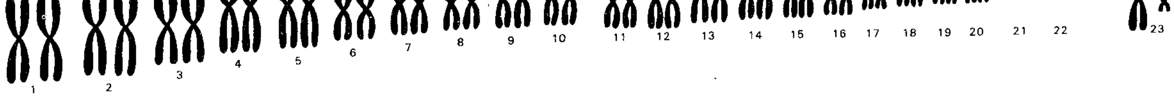
The conclusion of the article by *Jill Turner* — titled " 'Progressive' Thinking — Reducing the Risk of Mongolism" which appeared in the Spring newsletter of London's **Human Right's Society Newsletter** contains a most interesting and perceptive observation — **"The Glasgow Paper** on prenatal testing (published in the British Journal of Preventative and Social Medicine) points out that whereas the termination of affected pregnancies is lawful and acceptable to 70 percent of the population (1974 Survey by *Action Research* for the Crippled Child), euthanasia of affected newborn children is not.

The cost of screening, it adds contentiously might be regarded as payment for a scruple. (emphasis added)

So wide spread is the application of prenatal killing of genetically defective children as the 'treatment of choice' for mongolism that Jerome Lejeune, M.D. the world-famous geneticist and **discoverer of the basis of mongolism,** has refused to test for mongolism via amniocentesis as he could not lie about the outcome. "If I discover the child will be mongoloid, then I should have to tell the mother, in which case she may decide she wants an abortion. I am against all kind of killing. I am a doctor, and do not want to join some kind of disposal service.[55]

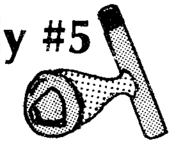
Summary

The National Foundation on the other hand, as demonstrated by its continuing popularization of amniocentesis for chromosomal disorders including Down's Syndrome — for which we repeat, there is no known prenatal treatment — has no objection to such a genetic disposal service providing the parents agree and a medical *technician* is available to carry out the killing. NF-MOD **funding** of such 'services' under its regular programs is generally not an issue since insurance programs — private or governmental — usually cover the cost of the amniocentesis and selective abortion. The National Foundation's funding of abortions connected with genetic research programs, however, is not so clear cut as indicated in the Yale Case Study.



TAY-SACHS: Prototype For Prevention of Genetic Disease?

Case Study #5



In 1975 the NF-MOD sponsored its first **Science Communication Conference** in Harbor Springs, Michigan to evaluate the status of research on genetic defects from a number of different perspectives.

The issue of **Developmental Bioethics** and the spectre of moral questions arising from the utilization and application of genetic-related technology was addressed by NF grantee **Dr. Michael M. Kaback,** a specialist in Tay-Sachs disease and Professor of Pediatrics, UCLA, and Associate Chief of the Division of Medical Genetics at Harbor General Hospital — UCLA. A review of his paper appeared in a subsequent issue of **Contemporary OB-GYN** in mid-1976.[56]

In his opening remarks, Dr. Kaback lists three basic considerations for a mass screening program —

1. The nature, frequency, and distribution of the disorder
2. The availability of a safe, accurate, and inexpensive screening test
3. The benefits to be derived by the individual found to be a carrier

— and notes that such programs bring with them a number of problems related to informed consent, coercion, and the right **not** to know.

However, in contrast to these screening problems, Kaback states prenatal genetics diagnosis combined with selective abortion provides a very valuable alternative in genetic counseling especially in the control of recessive diseases such as Tay-Sachs disease and sickle cell anemia which permits the family at risk to "have the opportunity to have only children who will be unaffected, and as many as they wish."[57]

This case study involves a review of the NF's screening program for Tay-Sachs and an examination of the thesis — echoed by Kaback — that the elimination of a disease can be accomplished by the elimination of the patient.

Causes and Characteristics

Tay-Sachs disease (TSD) is an inborn metabolic disorder which primarily affects children of Ashkenazi (Eastern European) Jews.

"Most Tay-Sachs babies are beautiful . . . they appear healthy at birth and develop normally for the first three to six months . . . gradually the central nervous system degenerates . . . and by 8 to 12 months, the child becomes paralyzed and blind and . . . requires hospitalization and/or long-term intensive care in the home . . . the average age at death is 40 months."[58] It should be added however that the hardship is mostly on the parents since most affected children are not in pain.

Tay-Sachs results from an absence of an enzyme called hexosaminidas A (Hex A) which is an *integral* part of body metabolism necessary for the utilization and control of lepids. Without Hex A, fatty substances known as sphingolipids accumulate in the cells of the brain and nervous system resulting in physical and mental retardation and eventual death. "There is no known cure, and no early prospect for one."[59]

The enzyme deficiency for TSD was identified in 1968 — a discovery which paved the way for both prenatal diagnosis, and mass screening for carrier detection and within two years programs of mass screening of the Ashkenazi Jewish population for detection of adult carriers were underway.

According to Kaback and his colleague O'Brien of the University of California, San Diego, who conducted one of the first amniocentesis and culture tests for TSD in the U.S., "The reasons for widespread interest in such programs, is **NOT** that TSD is that common, even amongst Jews, but rather that a simple blood test allows for complete prevention of this tragic genetic disease and at the same time enables couples, even if genetically at risk, to have unaffected children . . ." by monitoring (by amniocentesis) of couples identified by blood tests as at risk and *selectively completing* only those pregnancies in which an unaffected fetus is identified.[60]

Tay-Sachs disease was the first disorder which met the key criteria for prototype screening programs involving a recessive autosomal disease.*

First — TSD occurs 100 times more frequently in Ashkenazi Jews than in other Jewish groups and non-Jewish population thus limiting the 'target' to an immediate, easy-identifiably population.[61]

Secondly — The enzyme assay has been automated, making it possible to complete 300 serum assays per day, using either a blood sample obtained from a vein or fingertip.

Thirdly — Early prenatal detection of the disorder in order to permit 'selective abortion' of the affected child in lieu of the non-existence of medical therapy.

Fourthly — Backing by the 'target' population of the TSD community screening programs.

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*The recent successful prenatal diagnosis of thalassemia (Cooley's Anemia) by Golbus and Kan and of sickle cell anemia by Nathan open the door for similar national screening programs combined with 'selective' abortion.

The San Diego Program

In the O'Brien Tay-Sachs program at the University of California, San Diego, between 1969-Jan. 1973, 39 pregnancies were monitored and 9 fetuses were found to be deficient in HEX A.

Of the 9 affected children, eight were aborted. The ninth pregnancy was continued because the amniocentesis occurred too late to carry out the abortion safely.

Children born of the 30 remaining pregnancies were found to be free of the disease.

The Washington-Baltimore Program (1971-73)

One of the most publicized mass screening programs for Tay-Sachs carrier detection among the AshKenazi Jewish population, directed by Dr. Kaback was begun in May, 1971 in the Washington-Baltimore area. Initial funds for the program, some $65,000 was raised chiefly from the private community, the John F. Kennedy Institute in Baltimore and the Maryland State Department of Health and Mental Hygene.[63]

More than 7,000 individuals were tested during the 14 month period, primarily married or engaged couples, at community facilities for a voluntary fee of $5 per serum test.

It is interesting to note that **unmarried** persons within the Ashkenazian Jewish community were discouraged from testing in order to avoid possible psychological problems should the test prove positive. Since a "positive alternative" — amniocentesis combined with therapeutic abortion, would be available, almost 90% decided to wait until **after** marriage to be tested.[64]

If a woman being tested was more than 4½ months pregnant, top priority was given to testing her husband ("pregnant husband"). And should his test prove positive or inconclusive, the couple was rushed immediately to the hospital for leukocyte and repeat serum assays in order to meet (what was appropriately called) the **dead**line for aborting an affected child.[65]

At the conclusion of the program, 11 couples were identified in which both man and wife carried the Tay-Sachs gene. Within one year of being identified, five of the eleven couples conceived and all elected to undergo amniocentesis testing in which one child was found to be affected and subsequently aborted.[66]

According to Dr. Kurt Hirschhorn of Mt. Sinai School of Medicine, a member of the NF's Medical Service Advisory Committee, "The Tay-Sachs situation is a perfect example of an untreatable but preventable disease in which voluntary screening has been enormously effective, at least in one pilot project under the direction of Dr. Michael M. Kaback in the Baltimore-Washington area."[67]

This supportive statement on Kaback's work made at a **Contemporary OB/GYN** Symposium on 'Ethics of Genetic Counseling' by a National Foundation March of Dimes Scientific Advisor in the early 1970's was eventually followed up by more tangible backing in the form of **direct** National Foundation Basic Research grants to Kaback which to date total almost $100,000 for Tay-Sachs public education, screening, and genetic counseling program.

The New England Program (1973-74)

In November 1973, the Massachusetts Chapter March of Dimes joined with Beth Israel Hospital and the Combined Jewish Philanthropies to underwrite the cost of the first New England mass screening programs for Tay-Sachs. The long term goal of the project is to screen the 70,000 Jews of child-bearing age in metropolitan Boston and to screen others as they reach child-bearing age.

The estimated cost of the first year was $80,000, $15,000 of which came from foundations including the MOD affiliate.

In a pre-publicity article on the screening project titled "New Test Combats Tay-Sachs Disease" on October 25th, **Boston Globe** writer Herb Black stated that —

> "A couple found at risk can take family planning action. One option is to have the wife undergo amniocentesis in the first 20 weeks of pregnancy. Taking fluid from the fetus will determine if the infant will be abnormal. If so, the pregnancy can be interrupted."[68]

The Arizona Program (1975)

In March 1975, Dr. Jay Cooper of the **March of Dimes-Arizona Tay-Sachs Prevention Committee** located in Phoenix, sent a letter to area physicians announcing plans for married couples of child-bearing age in the Jewish community in Phoenix.

The second paragraph of the Cooper letter reads as follows:

"In many instances, such techniques (i.e. amniocentesis) allow prevention of a disease since intrauterine diagnosis of an affected fetus can be legally followed by termination of pregnancy. Couples who would otherwise be at high risk with each pregnancy for a genetic disorder in their offspring can be assisted in this way to selectively have only unaffected children."

The accompanying brochure opens with — —

"You may have never heard of Tay-Sachs Disease, a brutal killer of infant children . . ." followed by information on the causes of TSD. In response to the question "Will Any Hospital Care For Tay-Sachs Children?" the brochure states "Unfortunately, few hospitals will accept children for long-term care, and when they do the cost is generally prohibitive."

Rather than face "very expensive" Tay-Sachs care, the brochure states that "prevention" will cost far less than the cost of care for children with this fatal disorder.

According to Kaback and O'Brien, the estimated cost of screening the entire Ashkenazi Jewish population in the U.S. would 'only' cost about one fifth to one third the cost of caring for affected children which ranges from 24-hour nursing care up to $180 a day, or hospital facilities between $10,000-$50,000 a year.[69] Many parents prefer the high cost of home care rather than placing their child in a state institution because they've become so attached to the child.

The Cooper letter from the MOD-Arizona Tay-Sachs Prevention Committee leaves no question as to the preferred 'therapy' of selective abortion to **'prevent'** this disease.

Current Tay-Sachs literature being circulated by National Headquarters, including a reprint of the Kaback-O'Brien article "Tay-Sachs: Prototype For Prevention of Genetic Disease" (1973), stresses prenatal amniocentesis following screening for at risk couples.

The NF-MOD brochure **Tay-Sachs Disease and Birth Defects Prevention** notes that the March of Dimes supports research in many areas including Tay-Sachs however "a time table cannot yet be predicted. That day will probably be decades ahead, but we can be encouraged that it will come."

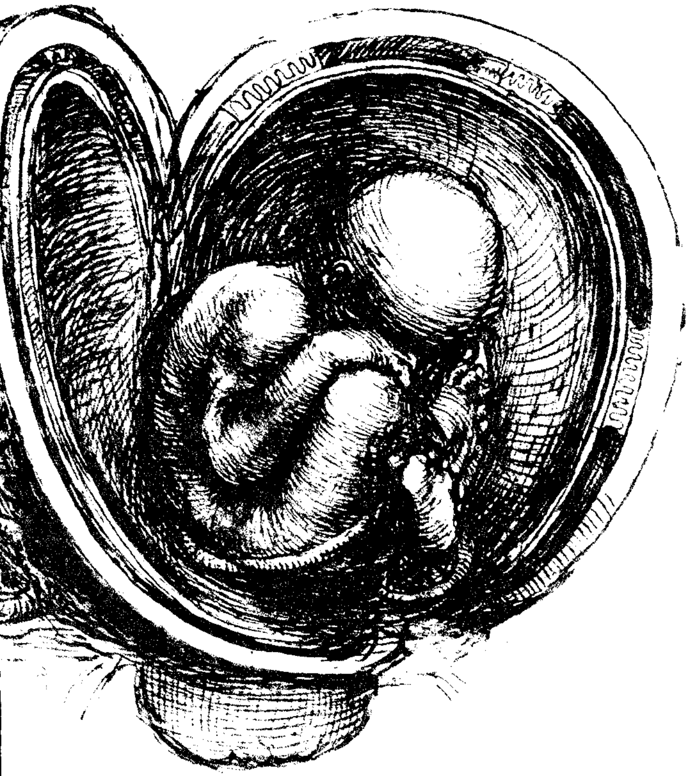
Sir A. William Liley, a U.S. Coalition for Life International Advisor from New Zealand and a pioneer in fetology in a Los Angeles Times article on amniocentesis in June, 1975 once remarked that theoretically there are ways which might be considered to prevent Tay-Sachs, other than abortion. But as long as it is decided that the management of Tay-Sachs is to abort the patient, little progress can be made in its prevention or cure.[70]

The National Foundation's bias toward 'selective abortion' in its literature is unquestionable. That it has chosen such a zealot apostle of 'selective abortion' as Dr. Kaback, to carry out model Tay-Sachs programs, is further evidence of such bias. The NF-MOD may look forward to the time when Tay-Sachs can be 'cured' or 'treated' — the question remains, however — will there be any Tay-Sachs children to cure?

* * *

> **"... In fact, the availability of abortion poses serious ethical problems for the exploration of more conservative therapeutic measures! These will be uncertain in the early stages and are therefore sure to result in a considerable residue of still damaged children either from insufficient control of the disease or as a side effect of the treatment. For these reasons, prenatal diagnosis and abortion will probably preempt other approaches to genetic therapy . . "***
>
> **Nobel Prize Winner Joshouha Lederberg**

*Lederberg, J. "The Genetics of Human Nature" Social Research p. 348



"EDUCATION FOR PARENTHOOD"

Case Study #6

NF-MOD Position on Family Planning and Young Parenthood

"Some 629,000 pregnancies were terminated by parental decision. These induced abortions are almost always the result of unplanned and unwanted pregnancies. While the National Foundation does not judge the morality of these parental decisions, we do believe that a very large proportion of this loss is avoidable through broader and more effective education and adequate family planning service to **all segments of the population."** (emphasis added)

NF-MOD Position on Family Planning
Gabriel Stickle
Vice President for Program — 1974

*NF-MOD Annual Report 1974

"No over-all plan for making serious inroads on infant mortality and morbidity can overlook its gravest aspect: The growing number of teenage mothers. Physical and psychological immaturity is . . . an important risk factor in pregnancy. Not only are teenage mothers ill-prepared physiologically to assume the double burden of carrying a child and completing their own maturation, they are also woefully ignorant of reproductive physiology and the benefits of early and regular prenatal care on their own and their baby's immediate future."

"The Foundation's leaders believe that this should become a permanent long-range part of its broad educational programs. **EXPERIENCE PERSUADES US THAT KNOWLEDGE OF THE CONSEQUENCES OF BEHAVIOR CAN CHANGE ATTITUDES, SO WE ARE GOING TO TRY TO CHANGE THE ATTITUDES OF THE SCHOOL-AGE POPULATION TOWARD THE WHOLE SUBJECT OF PARENTING."**

The terms "Education for Parenthood" (EP) which the National Foundation uses as a title for its 1974 Annual Report Section on teenagers and pregnancy, is identical to the Office of Child Development program instituted by the Department of Health, Education and Welfare in the Fall of 1972 under the **guise** of preparing teens for parenthood and helping young people to understand the basics of child development. Some of these Federal Programs on parenting turned out to be an anti-life boondoggle steeped in abortion, contraception, the Sangerite ethic — none of which are directed at **parenthood.**[71]

NF-MOD Funds EDC

The similarity in terms however is not the only similarity that exists as this case study will demonstrate.

In the first phase of the Federal Program of Education for Parenthood, an OCD-NIH award of $570,000 to the Social Studies Program of the **Educational Development Center** of Cambridge, Mass.

The EDC is best known in pro-life circles for its development of the controversial program M:ACOS (Man: A Course of Study) which was the subject of Congressional concern during the last session of Congress. The "non-profit" EDC operates primarily on government and private grants.

It therefore becomes somewhat unsettling to discover that the NF-MOD has awarded the Education Development Center a grant of nearly $75,000 for the development of a secondary school curriculum titled, "Will Our

Children Be Healthy?" According to the NF-MOD, "This comprehensive program is designed to prepare tomorrow's parents for decisions and responsibilities they will face as adults."[72]

The NF-MOD program will be ready for distribution in the Fall of 1977. It will be organized in three modules:

I. Adolescence, Sexuality, and Pregnancy
II. Where Life Begins: The Experience of Pregnancy and Parenthood
III. When Things Go Wrong: Birth Defects

The student materials and Teacher's Guide will contain discussion tapes; values clarification guides; and strategies for teaching as well as a selection of NF-MOD materials appropriate for grades 7-12.

Attitudes toward "parenthood", of course, involve the deepest of human emotions and is profound in its physical, mental social, and spiritual dimensions. Therefore, one is compelled to search out exactly what the National Foundation's leaders have in mind when they declare their new mission to be the **changing of attitudes** of the school-age population toward the whole subject of parenting.

Tomorrow is Today

"The Womb shall be his tomb and his first environment — his last."

from **Tomorrow Is Today** — An Evaluation
Randy Engel, U.S. Coalition for Life
March 10, 1975

"Tomorrow is Today" is an NF-MOD film strip which "talks about the environment of the womb . . . explores factors which may affect the unborn child . . . and challenges young people — sometimes quite explicitly — to take responsibility for the future by protecting their bodies from environmental hazards, including disease." (NF Promotional brochure) It is widely used in secondary classrooms and in conjunction with youth oriented programs including the BE-INS — **B**irth **E**ducation **INS**urance of the National Council of Catholic Women.

The following excerpts are selected from a lengthier evaluation prepared by USCL director Randy Engel at the request of Mary Keys (President) of the Waterloo Deanery Council of the Dubuque Archdiocesan Council of Catholic Women in March, 1975.

FILMSTRIP EVALUATION
*Introduction

"From the viewpoint of behavioral goals and values . . . the film strip . . . is one of the most incedious tools of anti-life indoctrination if only for the fact that the producers of the film go to such lengths to demonstrate their alleged concern for the unborn child — while they build a suitable case for his non-existence if he fails to meet the criteria of perfection."

*Factual Content

". . . in commenting on the preborn child, the film states that the **fetus has no control over this environment.** This conclusion is in direct contradiction to the testimony of world famed fetologist Sir William Liley who notes that the unborn child is responsible not only for the endoctrine success of pregnancy but he determines the homograft problem in pregnancy, and, in most cases, determines the duration of the pregnancy."

". . . Thus the fetal world is not a dark and silent world nor is he deprived of sensory deprivation . . . the unborn child clings tenaciously to his life even when his environment is invaded by drugs, etc."

"The filmstrip places heavy emphasis on a litany of pre-natal and post-natal complications associated with teenage pregnancies, and ignores the advances which have been made in obstetrical care for young mothers.* An exaggerated **fear** of pregnancy and of fetal defects is imparted while the consequences of induced abortion on the nuliparous patient is **totally** ignored . . . Scientific data supports the position that for the best maternal and fetal outlook, youth is a better ally than artifical child spacing and aged parenthood . . . Certainly a newly pregnant young girl viewing this film strip would acquire a poor image of her ability, physically and emotionally, to carry through with the pregnancy, and abortion appears as an escape from physical harm — for herself and her preborn child."

"Regarding the matter of genetic counseling in the true sense of the word — insofar as parents and other concerned persons are able to act and make **morally** licit decisions based on the knowledge acquired at such counseling sessions regarding risks, benefits, aid for affected children, etc. — this is good."

"Having made this qualification, it must be stated that the filmstrips coverage on genetic defects is poor . . . little attempt is made to explain that such defects include various degrees of severity . . . some are treatable while others are not . . . some involve serious mental and physical disorders . . . but many do not . . ."

"Again . . . the pattern of negativism is emphasized . . . little is said about the positive contribution that many handicapped persons make to society . . . nor of the fact that contribution or not — an unborn child — defect or not — has a right to live — as a child of God."

*The Pollution of the Womb

"While the filmstrip emphasizes the ill effects of environmental and pharmaceutical pollution in the womb, interesting enough the narrator fails to draw attention to the Pill and the IUD, both of which are predominantly abortifacients; i.e., their principle mode of action occurs at the uterine level to destroy the early embryo. On the other hand, the Sangerite creed with the emphasis on the "planned" and "wanted" child, permeates the filmstrip."

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* See Dwyer, J., M.D. "Managing The Teenage Pregnancy" on Alternatives to Abortion International (AAI) reprint from the **OB/GYN OBSERVER.** Author gives impressive data on the management of pregnant girls, ages 12-16 years, from a low socioeconomic area.

"The late Alan Guttmacher of P.P.-W.P. once suggested that the abortion battle could be won by convincing young people they should have total and absolute control over their "fertility." Since the film is directed at young, unmarried secondary students, what the film promotes would be more honestly labeled "fornication insurance" since no "family" exists for one to "plan!"

"The filmstrip treatment of venereal disease — within the context of Christian morality — is shabby. Chastity for the unmarried and fidelity for the wed are the "remedies" for VD. Anything else is but a stop-gap remedy — and doomed to failure. The subtle impression is given that since VD has reached epidemic proportions, such behavior can be equated as the norm for youth. The remark that treatment is available without parental consent or knowledge is, on the other hand, not subtle at all. References to the youth's need of personal counseling and familial support over the long haul would have been more appropriate.

*Conclusion

"The over-all impression reinforces a negative attitude toward new life in the womb which comes into being under **less** than optimal conditions because of

youthful parenthood
economic and material deprivation
genetic defects . . ."

Rather, a prolife version of the filmstrip would emphasize in part Christian virtues inside and outside of marriage, factual information of genetic defects with the emphasis on available therapy and accomplishments of handicapped persons, practical and pre and post-natal aides such as breastfeeding, etc., the wonder of fetology — the world of the unborn.

"Thus, the filmstrip — **"Tomorrow Is Today"** which fails **both** in **attitudes** and **in facts** should be rejected and replaced with a more **factual** and **prolife** viewpoint.

CONFERENCES ON ADOLESCENT CHILDBEARING

Several reports on National Foundation symposiums on early childbearing (1973 through 1976) usually held in co-operation with teen oriented groups such as the American Home Economics Association or Maternal-Child Health personnel, which this editor has reviewed, reinforce the Sangerite orientation of "Tomorrow is Today."

- On March 10, 1975, a symposium on "Childbearing in Adolescence" was presented in Washington, D.C.'s Shoreham-Americana by The Catholic University of American School of Nursing and co-sponsored by The National Capitol Area Chapter of the NF-MOD and the American Nurses Association.

One of the best attended seminars on "Counseling The Sexually Active Adolescent" featured four panelists

1. **A Representative of Planned Parenthood** who viewed most sexually active adolescents (including those 12-15 years old) as being beyond hope of sexual responsibility. Therefore, the emphasis should be on provision of contraception — backed by abortion.
2. **"I'm VD Free — Are You?** was a button sported by a VD specialist from Atlanta who sounded the alarm on the VD epidemic including the Herpes strain.
3. **A young, liberated feminist** who stated masturbation was preferable to sexual intercourse for young boys and girls who are "sexually excited!"
4. **A female physician** who stressed contraception — especially the condon, to reduce teen pregnancies.

- On March 26-27, 1975 a "Symposium On The Pregnant Teenager" was presented by the Illinois Nurses Association and co-sponsored by the Metropolitan Chicago Chapter and Illinois Chapter of the NF-MOD and American Nurses Association at The Sheraton-Chicago Hotel.

One of the featured speakers was Planned-Parenthood's own Harriet Pilpel championed the reproductive rights of teenagers since "Teenage Pregnancy is Here To Stay!"

Emphasis was primarily on prevention of teen pregnancies by contraception backed by abortion. Continuing education and adequate medical, dental, nutritional care well considered essential to the teenage mother as well as emotional support and social acceptance.

A physician who addressed himself to the issue of teenage ob/gyn complications concluded his statement with the following message: "If we don't abort these young girls, there is a big job waiting out there, taking care of these girls and their babies!" He then denounced the Bartlett Amendment which is designed to cut off federal funds for abortion and urged its defeat. The crowd roared with thunderous applause.

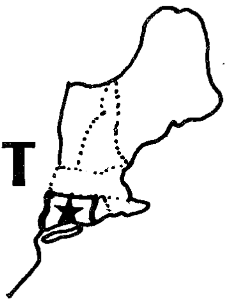
There was little information about the young male parent — his rights, his needs, etc. although two speakers who actually described teenage mother programs made some positive suggestions — but unfortunately, not enough to change the overall tone of the conference.

- On September 21, 1976, the Pennsylvania Congress of Parents and Teachers and the March of Dimes sponsored a conference titled "Parenting — Tomorrow Happens Today." The MOD representative presented what appeared to be incredably high statistics and erroneous "facts" on complications of adolescent pregnancies. A statement insinuating that children born to mothers who lack a sufficient education eventually become the trouble makers of society was made by the representative who suggested that only college-educated or trained persons are qualified to be caretakers of children of working mothers.

Perhaps the most intriguing question to be asked at this point — is how a voluntary "health" **agency** like the March of Dimes can consider itself a source of wisdom on the topic of "parenting?"

[*Editors Note: My appreciation to Mary Stone, Helen R. Fritz, R.N. and Mary Keys, for their assistance in the preparation of this case study.*]

THE YALE EXPERIMENT



Case Study #7

This scenario involves the extensive commingling of National Foundation-March of Dimes faculties, researchers, equipment and facilities at three major NF-MOD funded institutions — the **Yale University School of Medicine** (Yale-New Haven Hospital) — **Children's Hospital Medical Center** (Harvard Medical School) — and the **University of California,** San Francisco, School of Medicine (San Francsico Medical Center).

The principle characters include:

Maurice Jeremiah Mahoney, M.D. — NF grantee; Associate Professor of Human Genetics and Pediatrics, Yale-New Haven.

John C. Hobbins, M.D. — Associate Professor of Obstetrics, Yale-New Haven.

Y. Edward Hsia, B.M., D.C.H. — NF grantee; Associate Professor of Human Genetics and Pediatrics; Director of Yale University School of Medicine Genetics Clinic.

Leon E. Rosenberg, M.D. — Chairman of the Department of Human Genetics at Yale University; attending physician, Yale-New Haven Hospital; member of the NF-MOD Clinical Research Advisory Committee.

David G. Nathan, M.D. — Chief, Division of Hematology, Children's Hospital Medical Center; Associate Professor Pediatrics, Harvard Medical School; NF grantee; Member of NF — Basil O'Connor Starter Research Advisory Committee.

Blanche Alter, M.D. — NF grantee; Children's Hospital Medical Center.

Mitchell S. Golbus, M.D. — NF grantee; Director, Prenatal Detection Program; Associate Professor, Department of OB/GYN and Pediatrics, University of California, San Francisco.

Yuet Wai Kan, M.D. — NF grantee; Hemotologist, University of California, San Francisco.

Charles J. Epstein, M.D. — Department of Pediatrics, University of California, San Francisco.

Melvin M. Grumbach, M.D. — Chairman, Department of Pediatrics, University of California, San Francisco, member NF Basic Research Advisory Committee, Chairman NF Clinical Research Advisory Committee.

Leon Speroff, M.D. — Assistant Professor OB/GYN, Yale University School of Medicine.

Gerald Anderson, M.D. — Assistant Professor OB/GYN, Yale University School of Medicine.

The combined sum of National Foundation-MOD research and medical services grants to the above institutions and specific investigators, as indicated between 1972-1976 (77) totals well over a million dollars from both NF-MOD chapters and national headquarters.

Fetoscopy — 'A New Era of Genetic Diagnosis'

In November, 1973 **Contemporary OB/GYN,** edited by Dr. John T. Queenan of the University of Louisville and a member of the National Foundation-MOD's Clinical Research Advisory Committee, featured a visit to Yale University in a lengthy article, appropriately titled, "Yale Explores the World of the Fetus."[73] In his 'Letter From the Editor' Dr. Queenan suggests that "A new era of genetic diagnosis may evolve from this project."[74] The key collaborators for the intrauterine fetal diagnosis experiment employing fetoscopy and ultrasound to obtain skin biopsies and fetal blood specimens to diagnose genetic diseases **not** decernable via amniocentesis, were **Drs. Hobbins** and **Mahoney** of Yale.

In late 1972, Mahoney, a specialist in metabolic-genetic disorders and cell culture and a participant in the National Amniocentesis Registry expressed dissatisfaction with routine amniocentesis procedures which could only reveal syndromes expressed within **disgarded** fetal cells, and shortly thereafter he enlisted the assistance of Hobbins, a specialist in untrasound and the development of fetoscopy — the principle task — to obtain fetal blood specimens during the second trimester of pregnancy for prenatal diagnosis.

In the first phase of the program emphasis was placed on the **visualization** of the fetus in utero and the amniotic cavity using an optical needle which Hobbins labeled a fetoscope following **ultrasonic monitoring** for proper needle placement. Later, **fetal blood samples** were drawn using a special blood-drawing needle developed by Hobbins and **skin biopsies** excised from fetal parts for culture studies. Both Mahoney and Hobbins expressed their fascination at the purposeful movement of the unborn child at twenty weeks gestation including sensitivity to light and resistance to visualization of genitalia.

All of the twenty-six women who participated in Phase I of the program were candidates for second-trimester abortions and were recruited from the Yale Abortion Referral Center known as FACTS (Family Advisory Counseling Treatment Service). Abortion fees are covered by campus and private insurance programs or by federal programs such as Medicaid.* The typical Hobbins-Mahoney fetoscopic abortion procedure employing prostaglandins was described in detail — —

Women desiring second-trimester abortion are evaluated by a social worker to determine if they're "psychologically suited to take part in the experiment." Suitable candidates are then interviewed by Hobbins, who describes the nature of the project and asks if they wish to participate.

Hobbins "explains that the meticulous use of ultrasound virtually ensures optimal selection of the site through which both the instruments and the aborting prostaglandins will be introduced. He adds that the average time of abortion for patients taking part in the project thus far has been identical to those not taking part . . ."

The day of the abortion the patient is greeted by nurse-midwife Sarah Dillian described as "an essential member of the clinical team," in the ultrasound room where the exact point for fetoscopy entry is determined.

With the fetoscope in place, Hobbins views the fetus and if possible locates a placental vessel. Mahoney monitors the oscilloscope screen while Dillian reassures the patient and assists Hobbins.

Then the fetoscope is removed and replaced by a blood-drawing needle in order to secure a fetal blood sample. A biopsy site is visually selected and skin samples are removed from the skin surface with forceps.

After the procedure is over, the team prepares the patient for the abortion which "is initiated by introducing a 40-mg dose of prostaglandins through a catheter, which is left in place until the abortion is completed."

The investigators had been a bit apprehensive about discussing the fetus immediately before aborting it. "We figured it might be unpleasant for the mother to hear us talking about how the fetus looks or moves, but we haven't had any real problems yet," Hobbins explains.[75]

Hobbins and Mahoney explain that Phase II of the project will help determine if the fetoscope procedure **itself** might lead the patient to abort or cause damage to the fetus. During this period, second-trimester abortion candidates would undergo the fetoscopic procedure described above but the prostaglandins abortion would be done later. During this interval, the amniotic fluid could be analyzed to determine if placental bleeding had taken place and to see if the procedure lead to a spontaneous abortion. Following the abortion, the fetus could be examined for damage incurred by the fetoscope.

Phase III of the program would employ a new group of patients — those who are contemplating abortion because they suspect they're carrying a defective child, but who will carry the child to term **if** the procedure indicates the child is free from the specific blood disorder, usually sickle cell anemia or thalassemia.

In the final phase of the program, fetoscopy — if proven safe — would be employed as a general diagnostic tool to determine, prenatally, the existence of certain genetic and other disorders in the fetus, and in a **few** cases, open the door for fetal therapy.

Hobbins and Mahoney note that they plan on tapping the talents of pediatric hematologist David Nathan at Harvard to assist in their blood assays. They also point out that while the same groups of diseases related to metabolic malfunctions require **pure** blood samples, other diseases can be determined from mixed maternal-fetal blood samples using the Nathan technique of antibody coagulation.

"Neutrality" In Counseling

In Phase III through V of the program, patients are generally referred to Hobbins and Mahoney from genetic counseling centers including the NF-MOD Center at Yale-New Haven headed by **NF-grantee Dr. Hsia.**

The November, 1973 **Contemporary OB/GYN** article under a subtitle "Genetic Counseling at Yale" describes a case study involving anencephaly, a central nervous system disorder resulting in severe crippling or mental retardation or death or both.

Dr. Hsia relates his experience with a young couple whose first child dies at birth from anencephaly, and who "still in a state of shock" are now seeking advice on whether or not to attempt a second pregnancy. After a thorough clinical workup Dr. Hsia explained to them "That it is now possible to diagnose anencephaly and many other nervous system defects early enough in pregnancy to give them the option of abortion. In describing the techniques used, such as fetoscopy, we mentioned the work of Dr. Hobbins and Mahoney but emphasized that their project is experimental . . ." The couple decided to try for another child and to take advantage of the best available prenatal diagnostic techniques.[76]

Dr. Hsia's lab-side manner appears rather mild when compared to the "counseling" techniques used by **Dr. Karles Adamsons** formerly of Columbia University (N.Y.) one of the National Foundation's best endowed research-medical centers.

According to David Rorvik, author of **Brave new baby — Promise and Peril of the Biological Revolution*** when Dr. Adamsons is faced with trying to persuade a mother from bearing a defective child and to get her to opt for an abortion he takes them on a selective tour of the hospital ". . . If necessary . . . we will take the mother to visit a group of incompetents (mongoloids and other retarded or deformed children) to help her realize what will happen if she insists on going through with the pregnancy."

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* *Rorvik, D.* **Brave New Baby-Promise and Peril of the Biological Revolution** Doubleday & Co. NY 171 Pgs. 68-69.

Rorvik's book which was published in 1971, two years before the Supreme Court decision of January 22, 1973 contains some other choice quotes by a number of geneticists employed at well-known Foundation research and medical service centers including **Dr. Sheldon Cherry** of Mt. Sinai (N.Y.) where Adamsons is currently working.

"What good are all these advances (i.e. prenatal diagnosis/amniocentesis) . . . if a woman finds out her baby is going to be an idiot and then can't get an abortion," laments Dr. Cherry.

His views are supported by geneticists Harold Klinger and Orlando Miller who note that breakthroughs in chromosomal analysis "will be of limited significance if more liberalized medical abortion laws are not instituted in the United States."

Update on Fetoscopy[77]

Some two years later, the **Contemporary OB/GYN** team returned to Yale to obtain an update on fetoscopy which editor and NF Scientific Advisor Queenan describes as an important "resource" in major centers especially for the prenatal diagnosis of thalassemia and sickle cell.[78]

— A Financial Profile of Participants —

As noted earlier in our introduction Yale-New Haven has been the recipient of long-term extensive NF-MOD medical services grants averaging approximately $30,000 plus a year. Dr. Hsia has been the recipient of NF-MOD and HEW-PHS funds to develop the Yale genetic counseling program. Between 1974-1976 Mahoney had received more than $60,000 NF research funds for "carrier identification, prenatal diagnosis and treatment of genetic defect of vitamin B12 metabolism."[79] Nathan, who had begun receiving NF-MOD research funds had accumulated more than $100,000 for "devising a way to distinguish fetuses with sickle cell anemia or beta-thalassemia (Cooley's anemia) from normal or carrier fetuses . . . using placental blood obtained by amniocentesis . . ."[80] and later "prenatal detection of sickle cell anemia and thalassemia."[81]

Nathan's latest NF-Basil grant of $37,655 is "to develop **biochemical** and **fetoscopic** techniques for obtaining and analyzing fetal blood for the prenatal diagnosis of sickle cell anemia and thalassemia.[82]

Mitchell Golbus, M.D., who participated in the Yale Experiment received more than $50,000 in NF funds conducted his research on new prenatal diagnosis techniques and fetal tissue and amniotic fluid preservation and storage at the University of California, San Francisco School of Medicine whose million dollar plus NF-MOD genetics program is directed by Dr. Charles Epstein.

In "Fetoscopy Emerges As A Clinical Tool" the **Contemporary OB/GYN** reporter recaps the early work of Hobbins and Mahoney and then proceeds to describe the advanced stages of the Yale-fetoscopic program in the form of clinical testing using patients at risk of fetal disease who would spare their child from selective abortion **if** they could be reassured that the fetus was **normal.** Drs. Nathan and Alter of Boston's Children's Hospital were collaborators with Hobbins and Mahoney in the hemoglobin studies.

The following clinical profile is presented:

* A patient whose fetus is at risk for B-thalassemia major undergoes two Hobbins-Mahoney procedures to obtain fetal blood samples. The fetus was diagnosed as normal and "the pregnancy was allowed to continue."[83]

* Four patients under fetoscopy for the determination of fetal hemoglobinopathies — **three** who are "allowed to continue" their pregnancies deliver normal children.

  The studies of the fourth patient indicate the baby has thalassemia major. However since this was one of the first in-utero diagnosis of a hemoglobinopathy, the patient was sent to the University of California, San Francisco for confirmation studies.

  The San Francisco research team of Golbus and Kan confirmed the Yale diagnosis. "An abortion was performed and the diagnosis was verified in the fetus."[84]

By late 1975, 15 case studies involving hemoglobin disorders and prenatal diagnosis by the Yale and San Francisco researchers using fetoscopy and placental aspiration were completed.[85]

The San Francisco Project

> *"NF grantees in 1975 announced several significant findings: Drs. Yuet Wai Kan and Mitchell Golbus performed the first successful prenatal diagnosis of thalassemia; Dr. David Nathan and associates reported the first successful prenatal diagnosis of sickle cell anemia . . ."*
>
> *from* **Highlights** *of NF History*
> *FACTS: 1977*

A more detailed report on the Golbus-Kan operation at the University of California, San Francisco School of Medicine is contained in the same January 1976 issue of **Contemporary OB/GYN** in a separate article titled "Prenatal Diagnosis of Genetic Disorders" by Mitchell S. Golbus, M.D.[86]

According to Golbus, his department had monitored 500 pregnancies by January 1976 for a wide variety of genetic disorders, with the following results:

Twelve fetuses were diagnosed for chromosomal disorders including Down's Syndrome and **ALL were aborted** and diagnosis confirmed on all "abortuses".

Thirteen fetuses were diagnosed for x-linked disorders. Eleven were aborted and diagnosis verified. The two survivors suffered from a **less severe** form of hemophilia. After birth, one child was diagnosed as 'normal' while the other had the suspected disease.

Seventeen fetuses were monitored for inborn-metabolic disorders, **all** six affected fetuses were aborted.

Sixteen fetuses examined for neutral tube defects were all diagnosed as free from the suspected disorder and the pregnancies were permitted to continue.[87]

These statistics indicate that **all** unborn children who were diagnosed as being **seriously** defective **were** routinely **aborted** under the Golbus program. The two sole survivors were spared only because they were diagnosed for a 'less serious' form of hemophilia.

The Rosenberg Statement

The possibility of treatment of the affected fetuses was not at issue since there is no known therapy for the disorders being diagnosed. Dr. Leon E. Rosenberg, Chairman of the Human Genetics Department of Yale explains the prognosis for treatment of most genetic diseases in the year 2000 — at a 1975 NF-MOD sponsored Science Communication Conference thusly — "I believe there is going to be very little advance in treatment **modalities** for chromosomal disorders and **multi**-factional traits. Nutritional avoidance for some disorders will continue to be a mainstay. Application of avoidance therapies will be enhanced by the widespread use of newborn metabolic screening programs . . . progress in replacement and activation therapies will be very uneven . . . genotypic modification will be more disappointing . . . prevention of conception, artificial fertilization of ova . . . artifical insemination will increase . . ." Dr. Rosenberg concludes his comments by noting that the public will be increasingly concerned with the **quality** in population control and that "social pressure will be particularly great regarding the economics of chronic care."[88]

Of the original 500 patients in the Golbus 3 miscarried within 7 days following amniocentesis, 7 miscarried between 18-50 days following amniocentesis and 20 miscarried a week **before** they were scheduled for their appointments at the San Francisco Center.

Dr. Golbus said he foresaw a new era of mass screening for the heterozygotes and increased use of prenatal diagnosis of hemoglobin disorders (ex. Tay-Sachs) using such techniques as placental aspiration and fetoscopy as well as the use of amniocentesis as "routine" for at risk patients.

Golbus notes that while he has done some fetoscopic work he prefers placental aspiration to obtain fetal blood samples because the latter procedure employs a smaller needle and thus less risk. On the other hand, according to Hobbins, fetoscopy permits direct visualization of the fetus, and fetal cells obtained by accompanying skin biopsies can be grown in half the time as cells obtained from amniotic fluid obtained by amniocentesis.

Insights into the Yale Abortion Program

It is not surprising that the second trimester abortions carried out by the Hobbins-Mahoney team employed prostaglandins, rather than hypertonic saline, since experimental prostaglandin studies have been conducted at the Yale University School of Medicine for many years.

According to Dr. Gerald Anderson of Yale between 1972-mid 1974, more than 1000 mid-trimester prostaglandin abortions were carried out at Yale with the cooperation of teams of obstetricians, residents and nurses. Compared with hypertonic-saline-induced abortions, prostaglandins appeared to have a failure rate of "essentially zero" with less maternal complications.[89]

In a special "Symposium" feature in Contemporary OB/GYN on **Prostaglandin Abortion** chaired by Leon Speroff, M.D. of Yale, Anderson addresses himself to the question of live births resulting from late prostaglandin abortions at Yale.

"We haven't had any (aborted babies) that have cried or have been breathing. Four or five fetuses have had spasmodic limb movement but none has survived . . ."

However with saline abortions, Dr. Anderson stated they'd had several. "We've thought for a long time what compound we could administer intra-amniotically that would decrease the possibility of any sign of fetal life. Live aborted fetuses can lead to rebellion by the nurses that could ruin the program."

Responding to a query on a shorter abortion time using urea and prostaglandins Anderson notes, "I'm not looking for an abortion time of eight hours; I just want to make sure the fetus isn't born alive."[90]

The Contemporary OB/GYN panel ends with a consensus that tax funds be used to train physicians in intra-amniotic abortions to which panelist Csapo responds "I think it should be our number one recommendation. Human lives are at stake!"[91] Another panelist, William Spellacy, a NF grantee concurs that such training is "certainly necessary."[92]

With this background it is easy to understand why members of the press reporting on the Edelin decision and its affects on abortion policies have sought public responses from a number of Yale personalities including Hsia and Hobbins as well as National Foundation grantees including Ken Ryan, Michael Kaback and Henry Nadler.

In an April, 1975 **Contemporary OB/GYN** article on the conviction of Kenneth Edelin for manslaughter, which has since been reversed, Hsia noted that while the Edelin ruling would probably not affect those patients who have been diagnosed as carrying a defective fetus it "may have an effect on how our obstetrics colleagues would respond to our recommendations."[93] Dr. Hobbins concluded that the Edelin decision would not alter anything they're doing at the Yale prostaglandin abortion project.[94]

Similarly, Mahoney, as the principal investigator of the National Commission for the Protection of Human Subject's contracted study "**The Nature and Extent of Research Involving Living Human Fetuses**" (see pgs. 1-1, 1-48 of the Commission Appendix) concludes with a recommendation **opposing** an outright ban of live fetal experimentation. It should be noted that the fetoscopic program at Yale by Mahoney and Hobbins conducted in anticipation of an abortion would be in jeopardy should Congress decide to reinstate a total live fetal experimentation ban except for **therapeutic** treatment directed at the unborn child.

The Humanity of the Unborn Child

In the same Commission Report (Appendix) containing the Mahoney study, Michael B. Bracken, M.P.H., Ph.D., Research Associate in Epidemiology at Yale University Medical School has a report on **The Stability of the Decision to Seek Induced Abortion** which contains some interesting figures and insights into Yale's experimental program involving abortions.

According to Bracken, the rate of change for **first-trimester** pregnant women at the Yale-New Haven Abortion Clinic, and Hospital who decide after 'counseling' **not** to abort was extremely low as demonstrated by the following figures:

Source	Year	Total # Abortion Referrals	# Who Changed Mind on Abortion	1% of Change
Hospital	1970-71	474	31	6.6%
Clinic	1972-73	395	2	.5%
Hospital	1972-73	3,887	30	.8%

The situation in the second-trimester however altered somewhat.

Bracken noted that almost 25% of the abortions at Yale are carried out in the second-trimester, and that such candidates were more agreeable to participating in 'research' projects in anticipation of abortion.

Of particular interest is Bracken's observation that research which emphasized the **humanity of the fetus** resulted in a greater degree of mind-changing in favor of delivery while research which involved danger to the fetus strengthened the woman's determination to abort the child. Thus Bracken recommends that research projects which violate the sensibilities of pre-abortion patients be avoided. However as noted earlier in this case study, Hobbins and Mahoney apparently were not detered in their discussion of the activities of the fetus in front of women awaiting the induction of the prostaglandin abortion.

Bracken explores his thesis further in the following paragraph.

> "In one Hungarian study 327 women were examined by ultrasonic Doppler technique within one hour of a requested first trimester abortion. The study sought to determine the efficiency of the Doppler technique, which has no risk to the fetus, in detecting fetal heart beats at various stages of pregnancy. While patients were not told the purpose of the ultrasonic Doppler examination, over 90 percent of the patients associated the audible sounds with the fetal heart. The reaction of the patients, especially the multigravidas on listening to the fetal heart sounds is of interest here. Among the multigravidas 60 percent were reported very disturbed by the sounds and immediately went into a long explanation rationalizing their decision to seek abortion to the medical staff. **A FURTHER 16 PERCENT CHANGED THEIR MINDS ABOUT THE ABORTION AND DECIDED TO BEAR THE PREGNANCY TO TERM.** (emphasis added) Among primigravidas 30 percent were disturbed by the experience and an additional 2 percent decided not to abort." (Commission Appendix p. 16-15).

If such a change of mind can occur in the first trimester of pregnancy one can but speculate how many Michaels could be spared from death by selective abortion at 20 or so weeks if parents were fully informed of the humanity of the unborn child by the counseling geneticists. Perhaps one of the reasons the National Foundation has consistently refused to develop a comprehensive guide on fetology for perspective clients — is the realization that the acknowledgment of the client of the humanity of the unborn child might well interfere with the decision to abort the affected child. Instead, the National Foundation finds public relations consolation in perpetuating the myth of "neutral" and "non-directive" genetic counseling as 'typified' by Dr. Hsia's presentation on anencephaly.

NF/MOD — Public Relations At Its Best

In its 1975 Annual Report, the National Foundation highlights the story of April Murphy — the first baby ever treated successfully in the womb, for an inherited, often fatal, vitamin deficiency known as methylmalonic acidemia which had already claimed the life of April's sister.

There are two forms of MMA, one responsive to massive doses of vitamin B-12, and the other not. According to the NF April proved to be lucky; she had the responsive kind.

The three persons credited with saving April's life were Dr. Mary Ampola who treated April and her mother at the NF-MOD Center at Boston Floating Hospital; Dr. Kay Tanaka, a Yale-NF researcher who monitored Mrs. Murphy's urine samples for acid levels and NF grantee Maurice Mahoney of Yale who conducted the analysis of amniotic fluid.

Although her treatment continues, April according to the MOD report is a "healthy, cheerful toddler," thanks to the three-way co-operation of the NF grantees.

We agree that April was 'lucky' to have a **treatable** form of MMA, for unborn children who are diagnosed to have serious genetic diseases for which treatment is **not** available as the Hobbins-Mahoney-Golbus studies show are marked for death by prenatal diagnosis — not life.

1976 WRAPUP

On December 23, 1976 **The New England Journal of Medicine** published a timely wrapup to this USCL Case Study titled "Prenatal Diagnosis of Hemoglobinopathies" — A Review of 15 Cases** authored by B. Alter, C.B. Modell, D. Fairweather, J.C. Hobbins, M.J. Mahoney, F.D. Frigoletto, A.S. Sherman and D. Nathan. (1437-1443).

The hemoglobinophy studies were carried out at four central locations

+Yale-New Haven Hospital, Yale Medical School
+Harvard Medical School
+Children's Hospital Medical Center, Sidney Farber Cancer Center, Boston Hospital for Women
+University of College Hospital Medical School (London, England)

The research was funded by a PHS grant, and grants from the National Foundation-March of Dimes and the Gordon Philanthropic Trust and Welcome Trust. Dr. Alter is the recipient of two research awards including a NF-MOD Basil O'Connor Starter Award.

Materials — Methods — Results

Between July 1974 and December 1975, fifteen 'high risk' patients underwent prenatal diagnosis — 4 for sickle cell disease and 11 for B-thalassemia. Both placental aspiration and fetoscopy were successfully employed in obtaining sufficient fetal blood samples in utero in 12 out of the 15 cases studied.

In the sickle cell series — 2 preborn children were diagnosed as being unaffected and the pregnancies were permitted to continue; 1 preborn child was affected and aborted; 1 preborn child died as a result of premature labor induced by the placental aspiration.

In the thalassemia series — 7 preborn children were diagnosed as unaffected and the pregnancies were permitted to continue; 1 preborn child was unaffected by the amniotic sac suffered leakage; 2 affected preborn children were aborted; and 1 preborn child was 'electively' aborted despite the investigator's claim that the child would be a carrier only.

The researchers note that if the prenatal testing had **not** been available "the normal" babies might have been aborted. Interestingly, two couples who were "determined" to abort, whose tests were a 'failure', changed their minds and went through with the pregnancies and both children were free of the disease.

Complications

In the seven fetoscopy cases, no fetal losses were reported as a result of the procedure. However, in two cases two entries into the same uterus were required to obtain adequate blood specimens and in another, one attempt at aspiration was followed by two attempts with the fetoscope. There was one diagnostic error and a recommendation for a repeat procedure was made even though the sample in this case was adequate.

The employment of placental aspiration appeared to be more hazardous. Two cases involved two separate attempts before an adequate supply was obtained. One case proved totally unsuccessful. In another case the placenta was aspirated about a dozen times to produce the desired yeild.

Four days after an aspiration, one patient spontaneously aborted at about 18½ weeks gestation and the child died from prematurity.

The results of the series lead the authors to conclude that "the mid-trimester uterus and placenta may not tolerate well repeated needle passage."

Also there appeared to be difficulties in the biochemical procedures used to evaluate the specimens leading to errors in diagnosis.

Discussion Of The Series

The discussion text of the article opens with the following statement:

"Prenatal diagnosis of antenatal defects and selective abortion of homozygotes offers an opportunity to prospective affected parents to have children without fear."

However, the authors note that current prenatal diagnostic techniques for sickle cell and thalassemia fall short of the 'perfect' text which would

1 — correctly identify all homozygotes
2 — never confuse heterozygotes (i.e. carriers of the traits)
3 — cause no fetal mortality

Their conclusion based on this 15 case studies is that these procedures remain "strictly investigative" and "must be performed with great caution".

A Fitting Epilogue

The day this report went to print, a USCL representative sent me a copy of an OB/GYN article titled "Maternal Serum and Amniotic Fluid Alpha-Fetoprotein as a Marker of Acute Fetal Distress in a Mid-trimester Abortion Model," authored by R. Weiss, J. Marci (A NF-MOD $13,000 grantee for 75-76), J. Robbins, and K. Elligers. The article had been submitted for publication May 17, 1976.

The research involved 18 healthy second-trimester abortion patients and was funded in part by the National Foundation and the Easter Seal Research Foundation of the National Society for Crippled Children and Adults. The data from the study indicated a major fetomaternal transplacental route for alpha-FP.

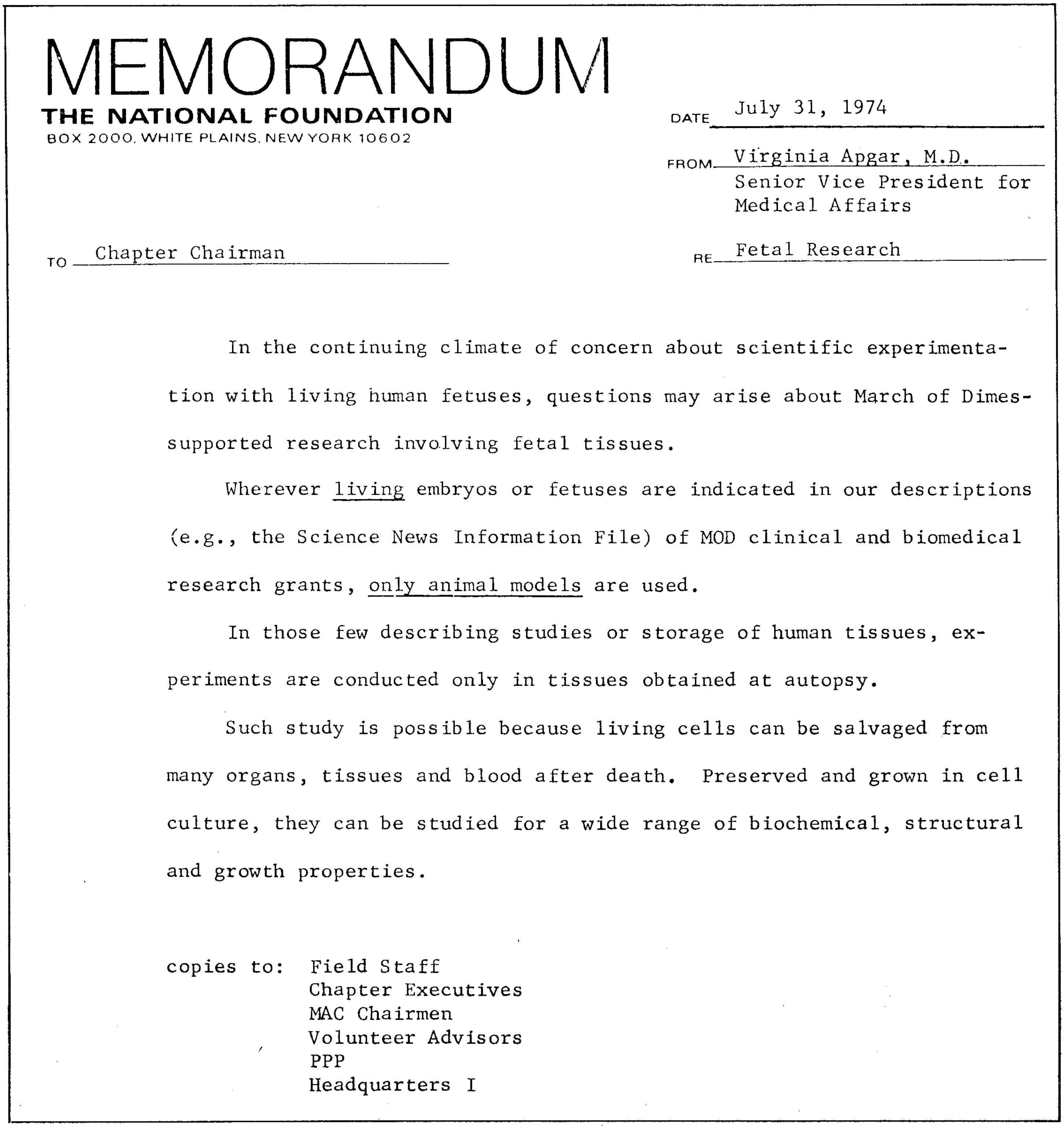
**As of November 20, 1976, 36 fetuses had been studied. Of these 15 were born normal as predicted; 7 women remain pregnant; 3 died of procedural complications; and the remaining 11 either "selectively" or "electively" aborted.

ACKNOWLEDGEMENT

Research assistant for this case study was Mr. Gerry McMahon of New Haven, Conn.

THE ADAM GRANT AND FETAL EXPERIMENTATION

Case Study #8



MEMORANDUM

THE NATIONAL FOUNDATION

BOX 2000, WHITE PLAINS, NEW YORK 10602

DATE July 31, 1974

FROM Virginia Apgar, M.D.
Senior Vice President for
Medical Affairs

TO Chapter Chairman

RE Fetal Research

In the continuing climate of concern about scientific experimentation with living human fetuses, questions may arise about March of Dimes-supported research involving fetal tissues.

Wherever living embryos or fetuses are indicated in our descriptions (e.g., the Science News Information File) of MOD clinical and biomedical research grants, only animal models are used.

In those few describing studies or storage of human tissues, experiments are conducted only in tissues obtained at autopsy.

Such study is possible because living cells can be salvaged from many organs, tissues and blood after death. Preserved and grown in cell culture, they can be studied for a wide range of biochemical, structural and growth properties.

copies to:
Field Staff
Chapter Executives
MAC Chairmen
Volunteer Advisors
PPP
Headquarters I

Medical World News Breaks Fetal Experimentation Story

The first this editor heard of the Adam grant was in a feature story in the June, 1973 issue of **Medical World News** titled "Post-Abortion Fetal Study Stirs Storm".

The **MWN** report noted that while the National Institutes of Health were pondering the future of fetal research in the U.S., conferres at a combined meeting in San Francisco in May, of the American Pediatric Society and the Society for Pediatric Research . . . heard a paper delivered by Dr. Peter A.J. Adam, associate professor of pediatrics at **Case Western Reserve University** in Cleveland on the **Metabolism of The Human Fetal Brain,** with no one even raising an eyebrow.

The Adam study of "cerebral oxidation of glucose and D-beta hydroxy butyrate (BOHB) in the isolated perfused human fetal head" was carried out in collaboration with Drs. Raiha, Rahiala, and Kekomaki at the University of Helsinki — and according to MWN supported **IN PART** by NIH funds (emphasis added).

The purpose of the study was to establish "whether glucose and BOHB can serve equally well as energy sources early in human development." The team's findings indicated they can and further, that there is no effective physiologic competition between the two fuels.

To produce this and other data, "the investigators severed the heads of the 12 pre-viable fetuses obtained by abdominal hysterotomy at 12 to 20 weeks gestation. The heads were then perfused through the internal carotid arteries with recirculating Kubs-Ringer bicarbonate medium containing labeled substrates, and were equilibrated continuously with a gaseous oxygen-carbon dioxide mixture. Venus return was obtained from the incised sagittal sinus, and carbon 14-labeled CO_2 evolved from the label substrates, was collected in hyamine hydroxide solution."

When interviewed about the ethics of non-therapeutic live fetal research, Dr. Adam states that no member of the Finnish-American team participated in the decision's regarding the method of abortion and that it would be both unethical and irrational **not** to take advantage of fetuses from abortions ". . . once society has declared the fetus dead and abrogated its rights . . . whose right are we going to protect when we've already decided the fetus won't live?"

The June **MWN** story on the Adam study came on the heels of a news story from San Francisco titled "U.S. Doctors in Europe . . . Operations on Live Fetuses"[96] describing in part, the activities of Robert Schwartz, M.D., Chief of Pediatrics at Cleveland Metropolitan General Hospital in Finland.

According to the Chronicle report, "After a fetus is delivered, while it is still linked to its mother by the umbilical cord, he takes a blood sample. Then, after the cord is severed, he (Schwartz), "as quickly as possible" operates on this aborted being to remove other tissues and organs." Schwartz was only one of several American scientists who traveled to Europe to obtain fresh fetal tissues and organs the article noted.

In addition to the fact that both investigators were doing **live non-therapeutic research on aborted fetus** and that they were both conducting their experiments at the **University of Helsinki** in Finland they both were associated with the same medical-university complex — **Cleveland Metro General Hospital — Case Western Reserve University.** These links were reinforced by the discovery that Dr. Schwartz was Dr. Adam's superior, and as the head pediatrics department at Cleveland Metropolitan General had approved of the 4-year Adams project. The question of funding remained however since the MWN article on Adams had noted that only **part** of his funds were from the NIH while the source of Dr. Schwartz's income in the San Francisco story was stated to be the Federal Governments' National Institute of Health (NIH).

The March of Dimes — and The Adams Grant

At the same time the live fetal experimentation controversy was making the headlines in many prolife newsletters, the controversy over amniocentesis and selective abortion and the National Foundation-March of Dimes had increased considerably. In reviewing the NF-MOD Facts Booklet for 1974, this editor noted that The Birth Defects Medical Service Program listing including a **$50,000 MSP grant to Cleveland Metropolitan General Hospital, Robert Schwartz, M.D. for "Genetic Services".** A quick check revealed that between 1968-1974, Cleveland Metropolitan General had received more than $170,000 in NF-MOD Medical Service funds. By 1976 that figure was up to $250,000. A brief two-line description of the "genetic services" provided, including genetic diagnosis, prenatal diagnosis, counseling and laboratory evaluations, was listed in the MSP Grants for 1975-76. There appeared to be no direct link between Schwartz's Helsinki "experiment" and the NF grants although as head of the pediatric department it is likely he received some benefits from the NF cash flow. Without obtaining a detailed financial accounting on the NF monies, which this editor has to date been unable to do — it is impossible to know how much, if any, MOD funds went to Schwartz in terms of salary, travel expenses, etc.

Fortunately, the Adam investigation proved to be more fruitful. On page 53 of the Facts-1974 the following description of the Adam grant appears — —

> Ohio
> Case Western Reserve University, Cleveland
> **Peter A.J. Adam, M.D.** $9,240
>
> To investigate in colaboration with the **University of Helsinki** in **Finland,** the basic **physiology of glucose metabolism in fetuses** at different stages of gestation, with the object of determining the sequential development of cell mechanisms in handling glucose and other substances used as fuel. Comparative studies are also being made between the cells of normal fetuses and fetuses of diabetic mothers.

The March of Dimes Responds

In April 1975 a letter was sent from the U.S. Coalition for Life to the National Foundation requesting an explanation of the Adams' grant.

On April 14, 1975, the following response was received from the NF-MOD National Headquarters in White Plains. The letter was singed by George P. Voss, V.P. for Public Relations who in the Fall of 1976 was replaced by Arthur A. Gallway, former V.P. for Development, NF-MOD.

> Randy Engel, Director
> Research Division
> U.S. Coalition for Life
> P O Box 315
> Export, Pa. 15632
>
> Dear Mr. Engel:
>
> I have checked into the purposes of our grant (no longer in operation) to Dr. Peter Adam. As you will note from the description, it had to do with glucose metabolism in fetuses. Specifically it was directed to a study of carbohydrated metabolism in the liver. The work of Dr. Adam performed under our grant did not involve heads, severed or unsevered, of fetuses. What other studies Dr. Adam did or did not pursue under someone elses grant I do not know.
>
> Upon re-reading your letter to the "Visitor,"* I noted especially this statement, ". . . MOD-NF activities and activists — many of which and many of whom espouse the proposition that the best way to eliminate defects is to eliminate the defectives."
>
> I repeat, you are saying that the foundation espouses abortion of defective fetuses. And I also repeat, it is not true.
>
> Sincerely,
>
> George P. Voss

The Investigation Continues

Clearly the Voss denial that the NF grant to Adam involved fetal heads at all, much less **severed** fetal heads, combined with the earlier Apgar memo on Fetal Research stating that "only animal models" were used in NF clerical and biomedical research grants, deserved further inquiry — perhaps both fetal heads **and** livers were involved.

This was plausable in light of the fact that the 1974 NF-MOD **ANNUAL REPORT,** which this editor had acquired quite by accident as a back copy, on page 28 gives a somewhat shorter version of the Adam grant than that found in the FACTS 1974 booklet —

OHIO	Peter A.J. Adam, M.D.	
Case Western Reserve University, Cleveland	$9,240	Fetal **BRAIN** fuel metabolism at different gestational ages.

Further, of the 68 NF-Birth Defects Research projects listed in the Facts 1974 Booklet, animal studies involving sheep, mice, monkeys, chicks, fish, amphibians, etc. are clearly identified — and **none** are referred to as "mothers" as in the Facts description which refers to diabetic "mothers". For example, the $42,734 grant to E.L. Makowski, M.D. of University of Colorado Medical Center on fetal brain metabolism indicates the use of fetal **lambs** in the study.

The fact that the grant involved the **University of Helsinki** also had to be considered. One reason the **S. F. Chronicle** article on Schwartz and other Americans gave for them going to Europe was that most U.S. abortions including early suction and saline abortions produce fragmented or dead fetuses and most of these experiments need whole, fresh specimens, preferably while the child is still attached to the mother. Obviously animal studies would present no problem here in the United States.

The investigation by the U.S. Coalition for Life continued through 1976. Here are the concluding facts, based on first-hand documents, on the Adam grant.

Adam's Research 1971-72

The initial application for funding of the Adam project titled — **Control of Fetal and Neonatal Glucose Metabolism** was approved by Dr. Robert Schwartz and submitted to the National Institute of Child Health and Human Development (NICHD) in June, 1971. The total period of the project was January 1, 1972 - December 31, 1975.

The application stated the project would involve the use of both human research subjects and the use of animals (pregnant dogs of known whelping date) and indicated that as principal investigator, Adam's major research interest was the "Development of the controls of carbohydrate metabolism in the **human** fetus and newborn infant."

Included on the list of current financial resources was the U.S. Public Health Service and the Cleveland Diabetes Fund ($8000) and the Association for Aid to Crippled Children ($6500) with the later grants reaching completion on 12/31/71 and 7/31/71, respectively.

Earlier Preliminary Studies by Adam

In his biographical sketch, Adam includes a paper on the placental transfer of human insulin which was published in **Diabetes** in 1969 (18:409). He lists himself as principle author along with **K. Yeramo, N. Raiha, D. Gitlin** and **R. Schwartz.**

As noted earlier, Dr. Raiha was one of the Finnish collaborators in the fetal head perfusion project with Dr. Adam and **both Dr. Schwartz** and **Dr. Gitlin,**[2] of the

---

* Visitor, the diocesan paper for the Diocese of St. Clous had carried a series of "letters to the Editor" on the MOD controversy to which this editor had written in support of the stance of Fr. Paul Marx.

University of Pittsburgh (on NIH grantee) are on record as making a number of trips to Scandanavia for fetal materials.

Dr. Adam indicated that preliminary investigations had been carried out on canine fetuses and **newborn dogs.** One model employed canine fetuses obtained by caesarian section which were decapitated immediately and handled similarly to the later **human** fetal purfusion studies conducted by Adam.

Dr. Adam also describes in detail four pilot experiments with his Finnish colleague Dr. Kekanaki carried out in order to evaluate the **feasibility** of studying human fetal hepatic glucose production, with substrates and labeled glucose. These preliminary studies, carried out by Adam and Kekanaki at the University of Helsinki in 1970, using 36 pre-born children (11-18 weeks in gestation) obtained by hysterotomy abortion **substantiated the feasibility** of studying the control of hepatic glucose production in the early human fetus between 14 and 16 weeks gestation. In these early pilot studies the **livers** of the 36 aborted babies were perfused in a manner similar to that described by **Medical World News** in the 1973 story on the Adam grant.

Description of The Adam Project for 1972-75

The NIH-grant application of course also included a detailed description of procedures and aims related to the project for which Adam was now seeking financial support.

Dr. Adam indicates that **pregnant dogs** (at later stages of development) would **initially** be used to determine the effects of maternal and fetal blood glucose concentration on postnatal glucose produced by the isolated prefused fetal dog liver at term. These preliminary studies are necessary for the proper development of experimental protocol prior to their application related to human fetuses and the newborn.

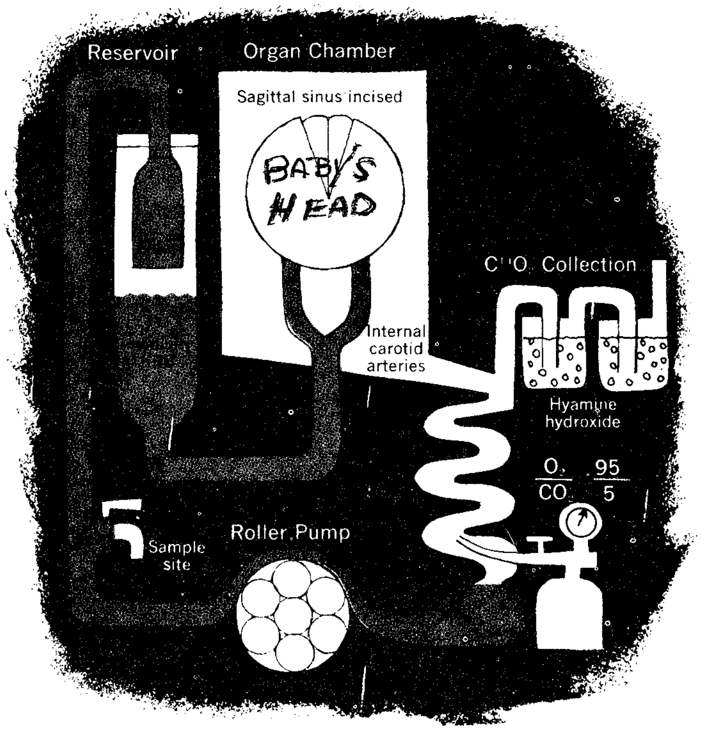
Facilities to be Used

At Cleveland Metropolitan General Hospital

A suite of laboratories was obtained by the pediatric metabolic service at CMGH for the assay studies. Human studies would be conducted at the Perinatal General Clinic Research Center. Separate housing and surgical facilities would be available for the animal studies.

Collaboration

Dr. Adam indicates **that Dr. Schwartz was instrumental in obtaining funds** to make collaboration studies with researchers at the University of Helsinki possible, especially Dr. Kekanaki. He noted that "seed" funds from the Association for Aid to Crippled Children and the Cleveland Diabetes Fund had made travel to Helsinki possible and had contributed "to the development of the methodology, and pilot experiments to examine the feasibility of Adam's new project. **As noted earlier, funds from these two later groups were scheduled to run out in 1971.** This meant that Schwartz had to seek other sources of travel funds and funds to maintain their Helsinki lab space and equipment if Adam was to continue his work there. It should be noted that from 1971-74 Adam was drawing his **basic** salary from a special PHS Research Fellowship. It appears that the government, however, preferred (or perhaps required) that Adam obtain Helsinki financial support from private foundations, particularly since the Finnish investigation involved the use of **living human beings.** This observation supported by the fact that the PHS grant given to Adam allocates $500 per year for **domestic** travel only.



With this system of perfusion, the Helsinki team was able to study the metabolism of the human fetal brain.

The Adam Grant Approved by the PHS

The Adam's grant for 1972 on **Control of Fetal and Neonatal Glucose Metabolism** was approved by the **NICHD,** as were his subsequent renewal grant contracts through 1974.

Following his initial year's project on dogs (1972) Adam expanded his work to include the development of methods to quantify hepatic (liver) glucose production in the **human fetus** and **newborn infant.** In the latter stages of the study this knowledge would be applied to aiding in the evaluation of pathophysiological abberations in infants with clinical hypoglycemia.

These renewal contracts, as do the original project application, require the principle investigator to list additional research support for the project.

On Page 4 (a) of the 1973 renewal contract (as pending) and page 4 of the 1974 contract (as awarded) the **National Foundation** is listed as a source of $9,240 for Adam's work on **Hormore-Fuel Interrelationships in the Human Fetus.** This sum corresponds to the grant Adam listed in the 1974 Facts booklet **for collaboration with the University of Helsinki on** the basic physiology of glucose metabolism in fetuses at different stages of gestation. The NF grant appears to have filled the financial gap left by the Crippled Child Association and the Diabetes Fund.

The contents of the information found in the renewal contracts for 1973 and 1974 provide the final supportive evidence that

First The National Foundation provided the $9,240 to Adam for collaboration work on glucose metabolism at the University of Helsinki.

Secondly that such collaboration included the use of living, human fetuses aborted by hysterotomy.

Thirdly, that such experimentation included the severance and purfusion of fetal heads and the removal of various organs from these preborn children was carried out under combined NIH-NF support.

How NF-MOD Research Projects Are Monitored

The monitoring of the use of funds granted by the National Foundation for any purpose is accomplished in several ways. All applicants must present a complete presentation of the work they will do and an itemized budget of proposed expenditures. The applications are scrutinized by staff and in most instances by an appropriate advisory committee on service or research. Progress reports detailing activities and accomplishments are required annually or semiannually. Accounting reports of expenditures are similarly required. Site visits are frequently made to grantees for direct observation of their activities.

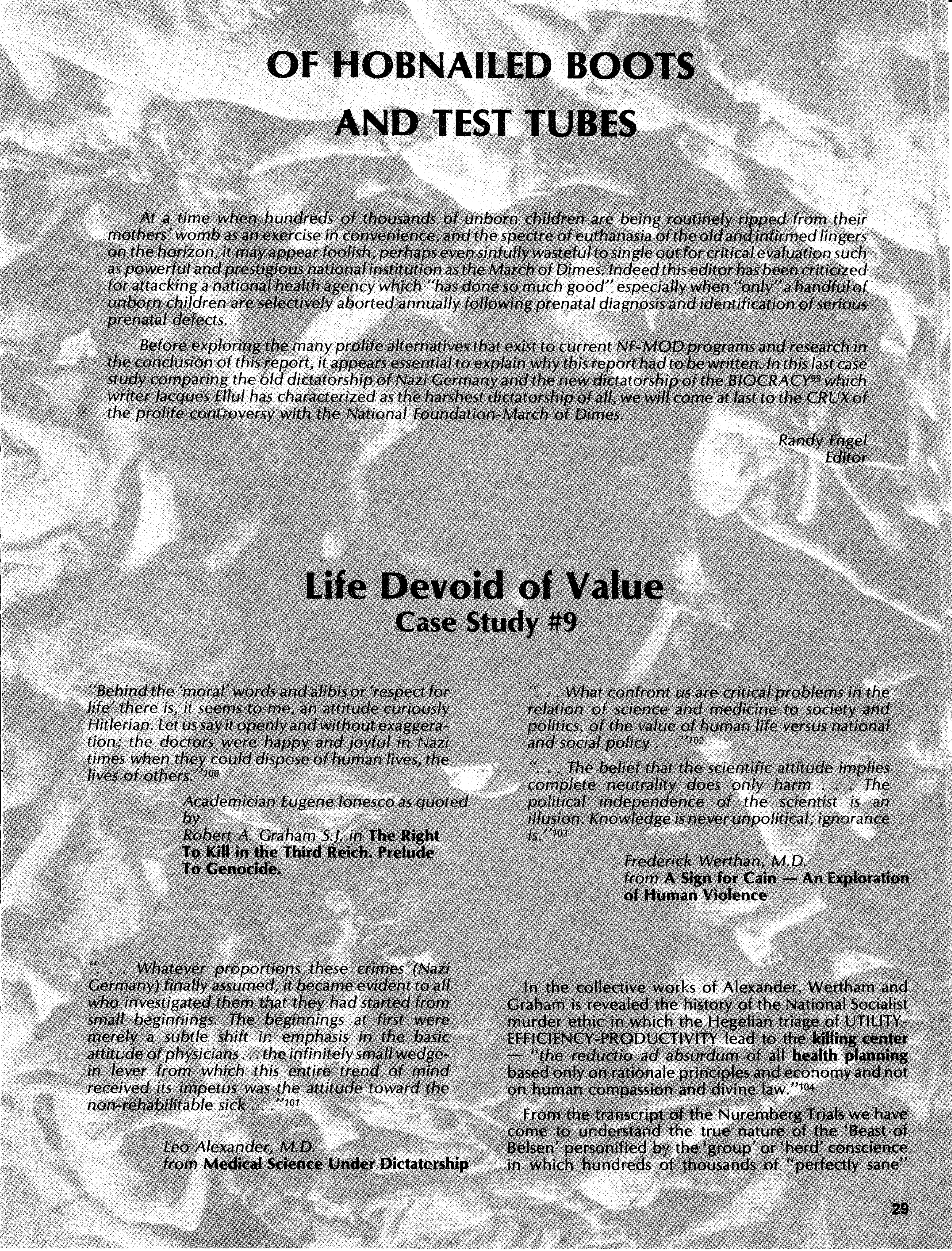
THESE MECHANISMS PROVIDE THE STAFF MEMBERS RESPONSIBLE FOR OUR SEVERAL GRANT PROGRAMS A FULL UNDERSTANDING OF THE USES OF FUNDS. Failure to conduct a program in the manner put forth in the application or deviation from our written policies, to which grantees ascribe in signing contracts for grants, results in termination of funding.

Statement by **Arthur J. Salisbury, M.D.**
V.P. for Medical Services NF-MOD
October 19, 1976

SUMMARY

After the Adam investigation, it comes as little surprise that a number of National Foundation grantees and scientific advisors who testified at the public hearings on Fetal Experimentation held by the National Commission on the Protection of Human Subjects opposed **any** federal restrictions on live fetal experimentation funding including such experimentation in anticipation of, or following, an induced abortion. Nor that these same people voiced a sigh of relief at the latest court ruling which overturned the Edelin conviction. This is particularly true since there are some well endowed National Foundation researchers such as Dr. F.S. Crocker of Nova Scotia who use routinely the kidneys of aborted preborn children in his work on congenital kidney malformation and functional abnormalities.[97] As our readers will recall, John F. Enders, Ph.D. of Harvard, received the Nobel Prize with Dr. Tom H. Weller more than twenty years ago for growing polio virus in tissue from aborted fetuses.[98]

Some like Dr. Ender may argue that tissue obtained from aborted babies is no different from those obtained at autopsy from natural death. But as the Adam study demonstrates, some can't even wait until the child is dead before claiming his flesh and organs — Shades of Dachau — which we will explore further in the conclusion of this report.



OF HOBNAILED BOOTS AND TEST TUBES

At a time when hundreds of thousands of unborn children are being routinely ripped from their mothers' womb as an exercise in convenience, and the spectre of euthanasia of the old and infirmed lingers on the horizon, it may appear foolish, perhaps even sinfully wasteful to single out for critical evaluation such as powerful and prestigious national institution as the March of Dimes. Indeed this editor has been criticized for attacking a national health agency which "has done so much good" especially when "only" a handful of unborn children are selectively aborted annually following prenatal diagnosis and identification of serious prenatal defects.

Before exploring the many prolife alternatives that exist to current NF-MOD programs and research in the conclusion of this report, it appears essential to explain why this report had to be written. In this last case study comparing the old dictatorship of Nazi Germany and the new dictatorship of the BIOCRACY[99] which writer Jacques Ellul has characterized as the harshest dictatorship of all, we will come at last to the CRUX of the prolife controversy with the National Foundation-March of Dimes.

Randy Engel
Editor

Life Devoid of Value

Case Study #9

"Behind the 'moral' words and alibis or 'respect for life' there is, it seems to me, an attitude curiously Hitlerian. Let us say it openly and without exaggeration: the doctors were happy and joyful in Nazi times when they could dispose of human lives, the lives of others."[100]

Academician Eugene Ionesco as quoted by
Robert A. Graham S.J. in **The Right To Kill in the Third Reich. Prelude To Genocide.**

". . . Whatever proportions these crimes (Nazi Germany) finally assumed, it became evident to all who investigated them that they had started from small beginnings. The beginnings at first were merely a subtle shift in emphasis in the basic attitude of physicians . . . the infinitely small wedge-in lever from which this entire trend of mind received its impetus was the attitude toward the non-rehabilitable sick . . ."[101]

Leo Alexander, M.D.
from **Medical Science Under Dictatorship**

". . . What confront us are critical problems in the relation of science and medicine to society and politics, of the value of human life versus national and social policy . . ."[102]

". . . The belief that the scientific attitude implies complete neutrality does only harm . . . The political independence of the scientist is an illusion. Knowledge is never unpolitical; ignorance is."[103]

Frederick Werthan, M.D.
from **A Sign for Cain — An Exploration of Human Violence**

In the collective works of Alexander, Wertham and Graham is revealed the history of the National Socialist murder ethic in which the Hegelian triage of UTILITY-EFFICIENCY-PRODUCTIVITY lead to the **killing center** — "*the reductio ad absurdum* of all **health planning** based only on rationale principles and economy and not on human compassion and divine law."[104]

From the transcript of the Nuremberg Trials we have come to understand the true nature of the 'Beast of Belsen' personified by the 'group' or 'herd' conscience in which hundreds of thousands of "perfectly sane" ordinary and in some cases extraordinary persons surrendered their own individual will and conscience to the State. Released from the burden of individual responsibility and personal guilt they assumed the corporate, public, official personality[105] — dehumanized — depersonalized — with delusions of omnipotence. These phenomena must be understood before the full meaning of the Nazi experience can be appreciated. For the hallmark of Nazi violence was **NOT** ideological fanaticism and hatred for its victims but rather total **INDIFFERENCE** to their fate.

Thus as English writer Caryll Houselander has suggested, the resistance to Hitler — who was "a symbol for every individual . . . the most prodigious personification of all human inferiorities . . . representing the shadow, the inferior part of everybody's personality, in an overwhelming degree . . ."[106] became in the end not so much a territorial war as a battle to retain our humanity!

From Physician To Technician

According to Dr. Leo Alexander who was an official American medical expert at the Nuremberg Trials of German physician-executioners of Nazi medical atrocities, Nazi propaganda was highly effective in molding the corporate-public conscience. The Medical profession was not immune from such propaganda and was marked by mass extermination of the chronically sick, of the socially disturbing and racially and ideologically unwanted and the ruthless use of 'human experimentation.'[107] Medical science had become an instrument of political power, a formidable, essential tool in the complete and effective manipulation of totalitarian control.

It is of great significance yet little known, that the first inmates of the "schools of genocide" were fellow Germans and Austrians. Between 80,000 - 100,000 — mentally ill, epileptics, feeble-minded, deformed — all identified as "lebensunwertis Leben" were killed without formality in brand new gas chambers mostly between 1940-41.[108]

The psycho-intellectual rationale for these killings had already been established in one of the most influential scientific works of the era **THE RELEASE OF THE DESTRUCTION OF LIFE DEVOIDS OF VALUE** published in Leipzig in 1920 and authored by two prominent scientists — Karl Binding and Alfred Hoche.

As early as 1931 'scientific' discussions of sterilization and euthanasia of persons with chronic mental illness were commonplace and by 1936 the extermination of the physically or socially unfit was openly accepted in the most respectable and prestigious circles of medical science.[109]

It was not until 1941 that the gas chambers and the crematoria were dismantled and sent to the East. "With them went the mad doctors and the graduates of the most sinister 'medical schools' in the history of humanity . . . The transition of Auschwitz was easy . . . And if it is permissible to kill, why not take the occasion for 'scientific' experiments on even healthy bodies . . ."[110]

As Wertham makes quite clear however the "mad" doctors who were the backbone of the euthanasia murders were hardly "mad". On the contrary they were the pillars of the academic community. "They were not nonentities or outsiders . . . most had all the hallmarks of civic and scientific respectability . . . some were full professors at universities . . . many are still quoted today in international psychiatric literature . . . the bibliography of their papers, monographs and books not to mention their graduate and postgraduate lectures . . . would fill a whole brochure . . ."[111]

Under the Nazi dictatorship the fundamental nature of the doctor-patient relationship had been drastically changed. Seen through the spectacles of utilitarianism, the 'patient' — be he man, woman or child — was no longer viewed as a human being in need of help, but rather an object whose value and disposition was determined by the State. The traditional role of the doctor as a healer, a protector, and a comforter was transformed into that of a mere medical technician who carried out his task as a matter of public utility without mercy or pity. Great stress was placed on economic factors i.e. the cost-benefit ratio of caring and helping as opposed to killing the patient.

It should be understood that while Hitler had given the medical scientists and physicians the POWER TO KILL he did not give them the ORDER to kill. There is a difference! The truth of the matter is however, as Wertham documents with chilling precision, no orders — no coercion was necessary for the doctors to do what they themselves wanted to do anyway.

As Dr. Christopher Hufeland had prophetized a century earlier, "If the physician presumes to take into consideration in his work whether a life has value or not, the consequences are boundless and the physician becomes the most dangerous man in the state."[112]

Human Experimentation

> "Even in ancient times, what we call primitive people made graves for the dead; they did not utilize or barter parts of the bodies. That was left to the civilized barbarians of **OUR** time."[113]

In Nazi Germany — ktenology — the science of killing reached the pinnacle of achievement in the utilization of the bodies of human beings, before as well as after death. This 'achievement' the scientists and physicians shared with private industry, pharmaceutical firms, and the military.[114]

There were three particular human experiments cited by Alexander which have particular relevance to this report, not so much for the nature of the experiment but rather for what they reveal of the attitudes of the experimenters themselves.

* * *

- As noted earlier, the mass exterminations included the mentally defective, the aged, and patients suffering from organic neurologic disorders such as infantile paralysis, Parkinsonism, multiple sclerosis and brain tumors.[115]

Among the benefactors of the treasure of human material made available for 'scientific' evaluation and study as a by-product of the euthanasia murders was a prominent neuropathologist, **Dr. Julius Hallervorden** who gave Alexander a vivid first hand account of his work.

According to Dr. Hallervorden, the Charitable Transport Company for the Sick, a euphanism for the euthanasia transportation squad, used to bring him batches of human brains 150 to 250 at a time. The specimens were always well fixed and suspended in formalin according to the doctor's explicit instructions, but unfortunately not carefully labeled since the victims suffering from a wide variety of disorders were exterminated in too large numbers to permit accurate identification and autopsies.

> "There was wonderful material . . . I accepted those brains of course. **WHERE THEY CAME FROM AND HOW THEY CAME TO ME WAS REALLY NONE OF MY BUSINESS."**[116] (emphasis added.)

- Experiments involving live dissections were carried out by Dr. Sigmund Rasher in the name of 'medicomomilitary' research. The subjects for the decompression studies were placed under water and dissected while the hearts were still beating, demonstrating air embolism in the blood vessels of the heart, liver, chest wall and brain."[117]

- By February 1942, German scientists feared the total anihilation of the Jewish race and they expressed dismay at the fact that not sufficient anthrological specimens of Jewish skulls and skeletons would be preserved for posterity. The task interested Dr. August Hirt of the University of Strassburg who promptly set up the mechanism for the project.

A selection of Jewish subjects, male and female were brought alive to Natzweiler concentration camp near Strassburg. Following their execution induced in a manner so as not to damage their heads, their bodies were brought to Dr. Hirt's anatomic facilities.[118]

Two common threads of rationalization run through the explanations of these and other medical scientists involved in human experimentation. First, the fact that the fate of their subjects was sealed and they were going to die anyway. Secondly, the fact that by using the bodies of the victims, they were merely taking advantage of a situation. Not to take the opportunity to advance medical science by using these human guinea pigs would have been in their eyes a waste of resources.

It should be noted that the projects were carried out, not in secret, but in the midst of populated university centers and hospital-laboratory centers with the knowledge and cooperation of a broad spectrum of the German population.

Down The Slippery Slope

The lesson of Nazi Germany is crystal clear — once the populace started down the slippery slopes of utilitarian ethics there was no internal corrective or brake to prevent the Holocaust. That such crimes occurred in the 20th century when nobody thought such acts possible, is worthy of deep contemplation.

It is not without a sense of pathos, that in the conclusion of his classic work, **Medical Science Under Dictatorship** written in 1949, Alexander cites the National Foundation for Infantile Paralysis — the forerunner of the National Foundation-March of Dimes — as an example of a healthy agency dedicated to the relief of human suffering and to the support and stimulation of medical research to bring "fresh motivating power into the ivory towers of academic medicine."[119]

* * *

The most deadly poison of our times is indifference.

Blessed Maximilian Mary Kolbe

The New Biocracy and the March of Dimes

A profile of the new 21st century dictatorship of the BIOCRACY is presented by the brilliant attorney William B. Ball in **POPULATION CONTROL: CIVIL AND CONSTITUTIONAL CONCERNS.**[120]

> *What is involved by the concept of population control is one aspect of that new domain by human activity described as "biological engineering". Engineering requires engineers, and engineers require standards . . . In the matter of establishing "proper" population levels we may speak of a "scientific" determination of such levels, but it will still be human beings who will make such awesome determinations . . . But engineering . . . while fully capable of attaining its goals according to its "tunnel vision", is never able to assess its single result in a total context of social result. Jacques Ellul sees as inevitable (but does not welcome) the complete triumph, by the year 2000, of a "biocracy" of which population engineering will be a feature: "in the domain of genetics, natural reproduction will be forbidden. A stable population will be necessary, and it will consist of the highest human types . . . "In comparison", Ellul says, "Hitler's was a trifling affair. That it is to be a dictatorship of test tubes rather than of hobnailed boots will not make it any less a dictatorship."*

The geneticists and medical scientists cited in this report on the National Foundation-March of Dimes represent the pioneers of the new frontier of the Biological Revolution described by Ellul. After reviewing their public statements and scientific papers, there is little doubt that most of these men, if it were possible to return in time to Nazi Germany, might find the setting somewhat strange but they would be perfectly at home in the company of the Nazi medical technicians and intelligencia.

Let us admit it openly and forthrightly, that these scientists of the new Biocracy have no more qualms or conscience about the destruction of innocent human beings in the womb — whose only crime is a failure to meet a standardized level of physical or mental endowment — than their predecessors who carried out the scientific, antiseptic, calculated killing of innocent human beings in the 'spic and span hell' of Nazi euthanasia wards and concentration camps.

Of all the parallels that may be drawn between the old and new dictatorships the following are perhaps the pertinent to this report — —

★The psycho-social-intellectual basis for both doctrines and the programs and policies which flow from them is **that there is in fact a life not worth living — that there exists a person who should have not been born at all.** This premise is reinforced by economic arguments — cost/benefit printouts — in which the costs of caring for an 'incurable' is held up against the costs of euthanasia — pre and post-natal — of such victims. What the Kabacks and Epsteins of this world cannot even begin to comprehend is that the price they put on the head of a Tay-Sachs or Down's Syndrome child is in the end a price which is put on the head of every member of the human family.

★In both the old and the new dictatorship, the traditional role of the physician is perverted and his concerns for his patient — which has always been of primary concern, is given second place to socio-economic considerations.

This perversion is particularly noticeable in the area of prenatal diagnosis programs promoted and funded by the NF-MOD. Foundation officials and grantees speak of saving preborn children from "unnecessary" abortions. But for whom is the abortion deemed "necessary" in the first place? Certainly not the fetus who is the primary patient. Rather, the term "necessary" is applicable to criteria of a familial or economic nature.

★In both the old and the new dictatorship, individual consciences and individual responsibilities are blunted and hidden by a 'corporate' entity which defends the indefensible by parading legal sanctions provided by the public authority for the destruction of innocent human lives. Euthanasia was 'legal' then. Abortion is legal now. Such destruction is excused behind a litany of euphanisms such as "the quality of life" and "necessary killing". The impact of this "corporate conscience" phenomena is evident in the statement of many National Foundation-March of Dimes volunteers and affiliate workers at the local and state administrative level who insist that while they are "personally" opposed to abortion, they must remain "neutral" in the matter when carrying out their professional-service obligations associated with their job. But how does one remain "neutral" to the killing of innocent human beings in the NF-MOD program whether it be carried out under the guise of genetic research or for the relief of the victim's family?

★In both cases the Hegelian ethic has replaced the traditional Christian-Jeudaic belief that **God** and not the State has the final word in the matter of life and death of a human being. Within the utilitarian ethic there is no room for human suffering to be sanctified and lifted up to the Creator as an offering of reparation for the sins of all mankind. Suffering is seen merely as a "useless" act and the release of suffering of the patient and in most cases the family, is seen as an act of mercy.

That such acts of 'mercy' can be limited to merely defective life in the womb is the same illusion that the Nazi medical profession harbored when they made the killing of the incurable their first order of business. Indeed there is already much public discussion about euthanasia programs for children with serious birth defects, and the incurably ill, particularly those in public institutions.

Conclusion

THE CRUX OF THE CONTROVERSY

In conclusion, having presented the facts and figures on a wide range of National Foundation-March of Dimes programs which challenge the agency's claim to 'neutrality' in the area of abortion, it may be important to point out that even **without** such evidence the position of 'neutrality' would be unacceptable. For in taking such a position and in asking that contributors, volunteers, staff and researchers abide by that position, the National Foundation-March of Dimes is asking each and every person to be indifferent of the fate of the future Michaels of this world. But to be indifferent to such children is to be indifferent to our own humanity, and that when all is said and done, may be to high a price to pay!

"Be Not Overcome by Evil, but Overcome Evil With Good." Romans 12:21

Prolife Alternatives To the March of Dimes

THE JUNIOR LIFE LEAGUE — He's My Brother!

The original concept of 'the Junior Life League' was presented to the U.S. Coalition for Life by Sister Dolores Brisson of New York as a vehicle whereby young people could contribute their time, talents and prayers for a wide range of prolife activities.

The U.S.C.L. would like to encourage the formation of Junior Life Leagues not only as a part of right-to-life groups but also at the elementary and secondary school level, on college campuses and within local community-based youth organizations. The three essential ingredients of Junior Life League activities would be: PRAYER - SERVICE - EDUCATION.

PRAYER

★★★★★★★ Daily group and/or individual prayer and reparation is the keystone of League activities since it is something that can be done by everyone regardless of age, location or circumstance.

SERVICE

★★★★★★★ Under the service program of the League, young people can offer their time, talents and energies **in the name of the League** to local community facilities for the physically and mentally handicapped; the aged; the infirmed as well as prolife groups and birthright-type programs designed to help both the unborn child and his mother. The theme of service may also be tied in with various prolife education programs in the community.

EDUCATION

★★★★★★★ The education element of the program offers a broad range of options for prolife young people. Funds raised in conjunction with such programs can be used to purchase equipment and supplies for prolife medical facilities, clinics and hospitals, for Birthright layettes, and for schools and institutions helping the handicapped and elderly.

Like all new programs, the Junior Life Leagues concept will undergo further development as actual programs begin to sprout up. For further information and communication on the Junior Life League program write:

JUNIOR LIFE LEAGUE
c/o USCL, Box 315, Export, Pa. 15632

Prolife Medical-Service Directories

Local and State prolife groups can develop a comprehensive and updated file which would contain among other resources (1) the names of prolife physicians who offer supportive genetic screening and counseling services to families seeking assistance in this area (2) the names of prolife physicians offering ob & gyn and pediatric care in the community (3) names of community hospitals and clinics which do **not** engage in abortions (4) information on private and public schools and facilities for the handicapped including general material on range of services, financial costs, contact persons, etc. (5) names of families with experience and/or which have a handicapped child who would be willing help with practical guidance and moral support for parents who are or may be faced with similar circumstances. (6) Literature on common birth defects such as Down's Syndrome along with materials on medical breakthroughs and advances in the prevention, care and treatment of such disorders.

These directories, in an attractive and simple format, can then be distributed throughout the community, to local clergymen, physicians, medical centers, schools and organizations for the handicapped, etc.

Of course many items listed as **Junior Life League** activities could be adopted to adult prolife programs including the donation of funds for special life saving and life giving equipment in wards for premature or handicapped infants and children. The offering of scholarships to promising students in the field of genetics, pediatrics, etc. is a project which may have applicability at both the state and national level.

THE MICHAEL FUND

International Foundation for Genetic Research

"The old idea that human beings are brothers is not an ethical hypothesis or a purely moral goal, but simply a correct expression of plain reality. The recognition of such brotherhood is very comforting, but increases our concern as human geneticists for the destiny of those unfortunate children who do not share equitably our chromosomal heritage."

"...We human geneticists have to face everyday reality: disabled children and distressed parents exist ... I believe that our response must be guided by two sentiments only — humility and compassion. Humility because we must recognize we have no ready made answers, because geneticists have not broken the secret of the human condition, and because scientific arguments are of little help in ethical issues; compassion because even the most disinherited belongs to our kin, because these victims are poorer than the poorest, and because the sorrow of parents cannot be consoled by science. But should we capitulate in the face of our own ignorance and propose to eliminate those we cannot help?"

"For millennia, medicine has striven to fight for life and health and against disease and death. Any reversal of the order of these terms of reference would entirely change medicine itself. It happens that nature does condemn. Our duty has always been not to inflict the sentence but to try to commute pain. In any foreseeable genetical trail I do not know enough to judge, but I feel enough to advocate."***

Geneticist Jerome LeJeune "On The Nature of Man"

In December 1976, Randy Engel, the Executive Director of the U.S. Coalition for Life and editor of the Special Report on the NF-MOD contacted the world reknowned geneticist Dr. Jerome LeJeune, Professor of Fundamental Genetics at the University Rene Descartes in Paris to inquire into the need and feasability of establishing an international foundation for genetic research based on the fundamental life principles as outlined in his lecture "On The Nature Of Man".

Dr. LeJeune, a pioneer in the study of Down's Syndrome not only responded with great enthusiasm but offered some practical guidelines for the program as well.

First he noted with sadness that the emphasis on abortion was slowly diminishing the intensity of research on the treatment of chromosomal diseases in the whole scientific world. Dr. LeJeune explained that dispite the potential for breakthroughs in prevention and treatment of Trisomy 21 (the Down's Syndrome which affects children like Michael) there is very little real scientific research being carried on in this field.

"We know by the history of medicine that it is not those who burned the plagued people inside their houses or those who stuffed rabies victims between two matresses who delivered humanity from the plague or from rabies (la rage)."

As envisioned by Dr. LeJeune, Foundation contribution would be equally divided for programs of (1) **medical services rehabilitation,** and (2) **research and clinical testing and treatment, of Down's Syndrome and similar chromosomal disorders** and eventually other inborn disorders.

Within the research sector of the program, existing facilities would be used, with emphasis placed on the development of institute teams composed of medical scientists and physicians from a number of disciplines including geneticists, chemists, psychologists, etc. The research centers would be large enough to accommodate from 10 to 20 beds for patients with serious complications and those involved in clinical investigation.

"I have no faith whatever in fundamental research in medicine which does not recognize **FIRST** the patient as a member of our kin nor could I imagine real and fruitful research if it is not stimulated everyday by the presence of the patients we are trying to help," Dr. LeJeune stated. According to Dr. LeJeune, the discovery of a treatment for Trisomy 21 — one which would be effective and respect fully the children and their parents can be achieved with much less effort and expenditure of both human intelligence and money, than it takes to put a man on the moon.

"A prolife foundation for genetic research could do a lot of good — It could stress to the world the need for an active therapeutic approach — It could in time... lead to the real victory — that is the victory against the disease, not against the patient."

"I fully agree that we have to care for and defend Michael . . . We can prevent the killing of innocent children only by forcing the victory. It is only when we are able to help them that others will desist from killing them," Dr. LeJeune concluded.

An Invitation For Life

Dr. LeJeune has graciously offered his assistances in helping to establish the new Foundation. He will be joined by a number of USCL Medical, Legal and Scientific Advisors from the United States, Europe, Australia and New Zealand. Preparations for laying the basic groundwork will be carried out by the Pennsylvania Foundation for Life, and are expected to begin this Spring.

The Pennsylvania Foundation for Life, based in Pittsburgh is established for the purpose of organizing, assembling and educating the public on the ramifications of abortion and abortion related issues, including the promotion of prenatal diagnosis combined with the selective abortion of defective children falls within the scope of its educational mandate.

"Your **tax-deductible** contribution to promote prolife genetic education, research and services and assist in the creation of an international center for the research and treatment of prenatal defects including chromosomal disorders may be sent to:

"Michael"
c/o Pennsylvania Foundation for Life
159 Hornaday Road
Pittsburgh, Pa. 15210

Whether or not this dream will become a reality will depend on many factors not the least of which are your prayers, encouragement and support. We began this special report with the question "WHO WILL DEFEND MICHAEL?" The answer is clear. For who else is there, but you and me!

Randy Engel
Randy Engel
Editor
The Prolife Reporter

*** Excerpts from Dr. LeJeune's speech to the American Society of Human Genetics in San Francisco, October 1969 upon the occasion of receiving the William Allan Memorial Award.

THE JEWEL OF MY CREATION

My child!
Before the dawn of Creation, I thought of you.
Before the mist blew through the heavens, I thought of you;
Before the blue water cascaded down the mountainside, I thought of you;
Before the first minnow jumped in a brook, I thought of you;
For you, my pet, are the jewel of My creation.
Before the dawn of Creation, I had a plan for you.
Your eyes are the color of a small sparrow's wing,
Your skin is as dark as the coal in the earth;
And again, your eyes are azure blue,
Your skin is brown like My mother's.
I had a plan for you from the dawn of Creation.
For centuries the grass blew softly on the great prairies.
Sometimes as softly as you breathe —
And the grass was waiting for you;
Yes, before the first crocus smiled at Me, I thought of your smile.
I will remember you into Eternity.
When the mist blows in the heavens no more, I will be with you;
When the blue water cascades down the mountains no more, I will be with you;
When the pine trees sprout forth no more, I will remember you.
My beautiful, My beloved! What are they doing to you?
My pet, My creation! What are they doing to you?
You lie on the table alone, You breathe so hard;
Will they not wash you with the blue waters of My mountains?
Your breathing is becoming so still, like the grass on the prairies in a great calm.
My child, I am thinking of you.
My beautiful, My beloved! What are they doing to you?
My pet, My creation! What are they doing to you?
Your little fingers are so small and soft, like a pussywillow's bud;
The steel from the cold earth;
Why do they press it to your soft new flesh with such great force?
My child, My thought is never removed from you.
My child, My beautiful! What are they doing to you?
With the suction, like a hurricane, they pull and tear you;
Your little legs will never walk, until you run with Me.
The salt in your mouth, when you were to sing for Me!
The salt in your lungs, you who were to yell of your love for Me!
Before the dawn of Creation, I thought of you.
I love you.
I will love you all of eternity.

C. Goering

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